

# **Disablism and Family Life**

Carmen Jarrett

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## ***Abstract***

Families with children with impairment experience disadvantage, but this disadvantage is rarely examined from the point of view of the social model of disability. The purpose of this study is to investigate the experience of families with children with impairment using the social model as articulated by Carol Thomas (1999). Thomas describes disablism as the exclusionary practices and prejudices that limit the lives of people with impairment. She thus includes both material and non-material dimensions in her understanding of disablism. Her model also acknowledges the role of impairment in creating barriers in the lives of people with impairment.

In order to identify what impact disablism has on families, if any, in depth interviews were conducted on two occasions with twelve families with children with impairment. These interviews were informed by ecocultural theory and explored how families with children with impairment organise their everyday lives. The everyday activities of these families revealed the social structures, institutions and practices in which they are embedded.

This study found evidence of disabling material barriers in family life in the form of constraints on mothers participating in the paid workforce, reduced family income, restrictions in family leisure opportunities, and problematic interactions with services. That is, much of the disadvantage in family life for families with children with impairment was socially created, rather than an inevitable consequence of their child's impairment. The results of the study also demonstrated that although families' psycho-emotional wellbeing was not undermined in the same way that Thomas

described for individual women with impairment, nevertheless prejudice experienced by families prevented them from participating in social life on an equal footing with their peers.

This study concludes therefore that disablism is not solely a phenomenon experienced by the individual with impairment; it is also part of the experience of family members of families with children with impairment. The thesis concludes by arguing the need for more appropriate social policy and practices that ensure that these families are not unfairly disadvantaged.

## ***Acknowledgements***

*Nel mezzo del cammin di nostra vita  
Mi ritrovai per una selva oscura,  
Che la diritta via era smarrita.*

These are the famous opening lines of Dante's *Divine Comedy*, about getting lost in dark woods in the middle of life's journey. I rather boldly wish to compare myself to Dante's narrator, in that I too got lost in the middle of the path of life and could not see the right way, except that I had strayed into academic work, rather than hell.

Dante's narrator had the poet Virgil to guide him on his journey, and my guide through the dark woods of making a thesis has been my supervisor Professor Gwynnyth Llewellyn. Professor Llewellyn sought to pull me back onto the academic path of clarity when I lurched off into the tangles and thickets of partiality, imprecision, and purple prose. Thank you, Gwynnyth.

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## ***Chapter 1***

### ***Introduction***

The term *disability* is used in such varied ways, both in everyday discourse and in various academic disciplines, that it could easily be added to Raymond Williams' list of "keywords" of social and cultural analysis. Williams described words of complex and varied meanings where "the problems of their meanings are inextricably bound up with the meaning of the problems they are being used to discuss" (Williams, 1983, p. 15). One popular understanding of disability is that it is something that a person has, a property of the person that makes them unable to do something that a "normal" person can do, because of the lack of a "normal" part or system within that person's mind or body. When disability is seen as an incapacity that is part of a person, the disadvantage experienced by a person labelled as "disabled" is readily seen as a natural or inevitable consequence of their "incapacity" or "lack".

However, such an understanding of disability as lack or incapacity has not gone unchallenged. Disability is also understood as arising, at least in part, from the social response to the person with impairment, as evidenced by the revision of the definition of disability by the World Health Organization (WHO, 2001). This definition of disability includes the environmental response to the disabled person as part of the

phenomenon of disability (WHO, 2001). Scholars who research in the area of disability also debate the meaning of the term disability. Across the chapters of the weighty *Handbook of Disability Studies* (Albrecht, Bury, & Seelman, 2001), for example, the term disability is used to mean the disadvantage of having an impairment and the disadvantaging social response to having an impairment.

The social model of disability has made a major contribution to the development of ideas about disability. Developed in the 1970s by people with physical impairments in the United Kingdom (UK) with the aim of improving their inferior life opportunities, the social model contested the idea that impairment causes disadvantage. The key way in which this was done within the social model was to draw a strong distinction between *impairment* and *disability*, and reserve the term disability for the disadvantage that is the result of the social response to impairment; disability is the disadvantage that is socially imposed on people with impairment. The social model spearheaded the increasing understanding of the extent to which the disadvantage that people with impairment experience is socially created rather than natural. Being socially created, this disadvantage is therefore theoretically amenable to social intervention.

Disability theorist Carol Thomas in 1999 presented her perspective on disability, or *disablism*, as a kind of social oppression akin to sexism or racism. Thomas defined disability as those social disadvantages that arise from social organisation which fails to take into account the needs of people with impairment. Thomas used both disability and disablism to describe the general process whereby people with impairment are marginalised by mainstream social arrangements, although within social model

theories more broadly disability is a more widely used term than disablism. Thomas describes disability and disablism as follows: “Disability becomes a particular form of unequal social relationship which manifests itself through exclusionary and oppressive practices – disablism – at the interpersonal, organizational, cultural and socio-structural levels in particular societal contexts. The challenge is to understand why and how disability takes particular forms in particular contexts. Like sexism and racism, disablism can operate consciously or unconsciously, directly or indirectly...” (Thomas, 1999, p. 40).

The social model, as Thomas has noted, has been put to good use in advancing the claims for social equality of people with impairment, but it has shortcomings. It is perhaps ironic that a model which emphasises that people with impairment as a group experience systematic disadvantage has not been applied to the family group to which the individual with impairment belongs. The situations of people of all ages and with varying kinds of impairment have been considered, but the situation of the family unit within which all individuals are located, including individuals with impairment, has been overlooked. This may be in part because some social modellists have considered families as a possible source of disablement for the individual member with impairment (Ryan & Runswick-Cole, 2008). It may also be in part because of the origins of the social model from within the ranks of working-age men with physical impairment (Morris, 1996). Whatever the reason, not considering the impact of disablism on families with children with impairment is unsatisfactory from several points of view.

The first reason to engage with how families experience disability is that social policy assumes that children with impairment live with their birth family, or at least live in a family, because children with impairment have the same right to a family life as any other child, as pronounced by the United Nations Convention on the Rights of the Child (UN, 1989). In high-income countries, social policy translates into services to support families to care for their children with impairment at home (e.g. in New South Wales, Australia, see DADHC (2004)). Despite these services, there is considerable evidence that families experience disadvantage, as I explain in more detail in Chapter 3. Whether this disadvantage for these families is caused by impairment or disablism is not known. The social model approach suggests that the dominant understanding of impairment as inability and tragedy masks the role of disablism in causing disadvantage. If disablism is the driver of the disadvantage experienced by families with children with impairment, then social policies built on the worthwhile foundation of promoting children's wellbeing may need closer examination to ensure there are no unintended negative effects. It therefore seems critical to investigate whether families of children with impairment experience the harms of disablism.

Secondly, families may have the potential to mediate and reduce the harmful effects of disablism if this exists for their child with impairment (Thomas, 1998). Family members, in particular mothers, can work to create opportunities for their child with impairment which can reduce and even overcome the disabling barriers that the child faces (Ryan & Runswick-Cole, 2008). If families do experience disablism because of their child with impairment, this may impinge on their ability to promote the wellbeing of their child, and therefore further add to the harms of disablism. For

children with impairment to receive the best possible start in life, any disabling disadvantage, no matter where it arises, needs to be addressed.

Thirdly, and from a theoretical perspective, social modellers have not accounted for whether disablism exists for family members, and if so, what its impact might be. In social model theory, the experience of disabling social barriers by people with impairment is understood as the outcome of an unequal social relationship between those with and those without impairment. Social model theorists argue that the nonimpaired are able to go about their business without concern for the disadvantage experienced by those with impairment, and therein lies a power imbalance (Abberley, 1987; Barnes, 1997). In accessing fulfilment of material and non-material needs, individuals with impairment as a group are pitted against the more powerful group of individuals without impairment. If family members of children with impairment who are not themselves impaired also experience socially imposed or created disadvantage, this imbalance in the social relationship which drives disablism needs to be understood and addressed.

These three reasons led to this study, the aim of which is to explore the relevance of disablism in the daily lives of families with children with impairment. Thomas' (1999) articulation of the social model was chosen based on her nuanced understanding of disability. Through investigating the personal experience of women with impairment she developed an understanding of disablism extending beyond the imposition of social barriers. She noted the harmful impact of impairment, which she called impairment effects, alongside the harmful effects of disablism. The disadvantage of disablism thus becomes, for Thomas, intertwined with impairment

effects in the lives of people with impairment, rather than standing alone as a socially created phenomenon. Thomas also extends the harm of disablism in restricting material activity to include psychic harm. From her work with women with impairment, she describes how negative and stereotyped meanings of impairment and disability can infiltrate their consciousness and undermine their psycho-emotional wellbeing. She thus extends the understanding of the influence of disablism in the life of the individual with impairment into parts of life that are often considered private, including identity and intimate relationships.

Thomas' model may also apply to the situation of families. This study takes a similar approach to Thomas by using the everyday life of the family to understand the influence of broader social structures upon the family. My method of choice was interviews focusing on families' everyday routines. This approach comes from ecocultural theory, which was developed to study families with children with developmental delay within their sociocultural context (Gallimore, Weisner, Kaufman, & Bernheimer, 1989). Ecocultural theory proposes that families actively work to create and maintain a routine of daily life. To understand this routine the family perspective is obtained from the point of view of the primary caregiver, that is, the person most responsible for organising the family's daily life. According to ecocultural theory, the social and cultural influences on a family can be understood from the primary caregiver's narrative of the family's everyday life.

This thesis which explores these issues is organised in the following manner. To explore the relevance of Thomas' model to the experience of families with a child with impairment, Chapter 2 details the concept of disablism, situates the theoretical

approach chosen within current debates about disablism, and details why Thomas' theoretical model was chosen for this study. Chapter 3 outlines the direction that research on families with a child with impairment has taken, and in particular what is known about disadvantage for these families, and then describes the gap in knowledge about these families from the social model perspective. Chapter 4 describes the research design, the choice of ecocultural theory and its accompanying narrative interview, the way in which data was collected in the interviews, and the analysis of data. Family life is examined in order to describe the impact of disablism on the material and non-material dimensions of family life, and the results are presented in Chapters 5 and 6 respectively. The implications of these findings for the concept of disablism and for understanding and supporting the work of families with children with impairment are then discussed, and some conclusions drawn, in Chapter 7.

## *Chapter 2*

### *Defining disability*

#### Introduction

The social model is not one single model. A range of approaches come under its banner. All share a core concern to identify and understand the way in which the disadvantage experienced by people with impairment is caused by societal responses to impairment. The apparent simplicity of redefining disability as a social process rather than as caused by impairment harbours considerable complexity.

This chapter outlines the origins of the social model and details some key criticisms. The way in which Thomas resolves these criticisms within her version of the social model is then presented. Thomas argues that restrictions in the lives of people with impairment are the result of both impairment and disablism, and that both impairment and disability have a place in creating the restrictions or barriers in the lives of people with impairment. She also argues that disablism operates in both material and non-material dimensions, and results in both structural disabling barriers and barriers of a more personal nature that arise from the impact of prejudice on identity and self-esteem. Thomas' approach opens up for investigation areas of personal relationship and identity, and the experience of impairment.

## The foundations of the social model

The foundational promulgation of the social model of disability was by a group of physically impaired activists from the Union of the Physically Impaired Against Segregation (UPIAS). In their position statement of 1976 (reproduced by Oliver, 1996), this group made a bold claim that disability is caused by social processes and not by bodily impairment. According to UPIAS, disability is caused by “contemporary social organisation which takes no or little account of people who have physical impairments” (Oliver, 1996, p. 22). This way of thinking about disability was very different from the conventional understanding of disability as inability, deficiency or lack within a person. UPIAS claimed that the restrictions or exclusions from the mainstream of social activity experienced by people with physical impairments are caused by the insensitivity of social organisation and structures rather than by impairment.

This redefinition of disability shifted attention from impairment to the socially imposed disadvantage experienced by people with impairment. The members of UPIAS wanted to live independently and be employed, rather than live in institutions and struggle on a government allowance. Their simple redefinition of disability offered a new way to think about and focus on the socially generated disadvantage they were experiencing, and to understand any social exclusions or barriers they experienced as central to this disadvantage, rather than as secondary to the primary “problem” of impairment.

The social model understanding of disability highlights the harm done to the identity of people with impairment when disability is understood as an inherent lack or

inability. For example, Oliver (1990) contrasted his exposition of the social model with what he called the individual or medical model of disability. He suggested that the understanding of disability as personal tragedy, which is part of the individual or medical model, is a limited and distorted representation of disability, created by others and imposed on disabled people. Subsequently he proposed that the medical model and the social model represented opposite ends of a continuum of understanding about impairment and disability (Oliver, 1996), with one end of the continuum representing disability as personal tragedy and coping with its consequences and the other end representing disability as the social creation of barriers. When impairment resides within, as in the individual (medical) model, it follows that people with impairment are held to blame or suffer the consequences of their unfortunate lack or incapacity.

The distinction between impairment and disability which was made in the UPIAS definition and reinforced by Oliver (1990, 1996) along with others (e.g. Barnes, Oliver, & Barton, 2002) was to become the hallmark of the social model. This distinction allowed the disadvantage of being disabled to be differentiated from the disadvantage of impairment. Once it was understood that not all the disadvantage of impairment resulted from the impairment itself, it became evident that, to a large degree, disadvantage arose from the social response to those with impairment. Socially imposed disadvantage is conceptualised as consequent upon impairment but not *caused* by it. To make this point, the early articulation of the social model by UPIAS members drew attention away from wheelchairs as a defining difference between wheelchair users and people without impairment, towards the social context in which there were many barriers for wheelchair users which prevented them from doing things they potentially could do, if physical and social environments were

designed differently. Not being able to walk was consequent to impairment, but limited choices in daily living, such as the inability to get a job or to get into a shop or restaurant due to being in a wheelchair, were socially imposed. This distinction between impairment and disability exposed the extent to which the disadvantage faced by wheelchair users, although commonly understood as the tragedy of impairment, was not a natural consequence of impairment. A provocative implication was that disadvantage, being socially imposed, could be changed, given societal will to do so.

Not surprisingly given the origin of the UPIAS statement, disability was understood by Oliver (1996) and others as a condition of a group, the group of people with impairment, rather than an individual phenomenon. For this reason, disability was to be tackled at the level of the group rather than the individual. The social model was a tool to focus on systemic discrimination rather than necessarily to combat exclusion at the level of the individual. As Barnes et al. (2002) argue, disability is combated by targeting the “various barriers, economic, political and social, constructed on top of impairment” (p. 5), and this is best done by addressing systemic exclusion: “Rather than identifying disability as an individual limitation, the social model identifies society as the problem, and looks to fundamental political and cultural changes to generate solutions” (p. 5).

The activists who originated the social model wanted improvement in the lives of people with impairment, and their purpose in distinguishing between impairment and disability was to identify and clarify the socially imposed disadvantage experienced by people with impairment which, being socially created, could be changed. In one

sense, their purpose in studying disability was not necessarily to understand disability, or why it is manifested in various ways, but ultimately to reduce and overcome it.

The social model has been credited with much success in achieving this activist aim. The extent of socially imposed disadvantage experienced by people with impairment is now widely known. Hughes (2007), for example, while critiquing the original promulgation of the social model's treatment of impairment and the body, at the same time noted the success with which this model articulated the socially imposed disadvantage of disability. He suggested that there was now a "vast amount of empirical evidence that indicates, with unquestionable clarity, that disabled people live lives marred by discrimination and exclusion" (p. 676). Thomas (2008) also argued that the social model has provided a foundation for a successful research direction, as evidenced in the contributions to the journal *Disability and Society*.

Much of the social model agenda has now reached the mainstream of disability studies. In particular, the core contention that disability is caused by the social environment is now recognised within official definitions of disability. The most recent World Health Organization (WHO) classification, the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) includes disability as socially imposed as one part of its definition of disability. The ICF definition recognises the central claim of the social model that the social response to impairment causes disability (Imrie, 2004). This prompted one commentator from within the social model community to recommend the ICF definition as follows: "The medico-psycho-social model which lies at the heart of the ICF does seem to me a sensible and practical way of understanding the complexity of disability"

(Shakespeare, 2006, p. 59). Other commentators are not as enthusiastic to adopt the ICF definition because of, from their perspective, a loss of focus on disability as socially created or constructed disadvantage (Thomas, 2008).

## Concerns about the social model

So far, I have described the origin of the social model and its success. In brief, the ICF definition gives a place to the core claim of the social model that the social response to impairment disables, and the social model has been credited with improving the lives of people with impairment (Oliver, 1996; Thomas, 1999). Despite these successes, there have been several key criticisms of the social model.

The strongly drawn distinction between impairment and disability made in the original UPIAS pronouncement and carried through in the writings of Oliver and others (e.g. Oliver, 1990, 1996; Barnes, 1991; Barnes et al., 2002), which has come to be known as the strong social model, has received particular attention. According to Oliver (1996), disability as socially imposed disadvantage is the focus of attention in the social model because social disadvantage has been sidelined in conventional understandings of disability and treated as part of the personal inability and individual misfortune or tragedy of impairment. However, the very strength of the distinction between impairment and disability of the strong social model that gives it such élan is also its theoretical Achilles heel. It has been argued that by focusing solely on disability, the strong social model ignores impairment, providing a unidimensional explanation of what is in fact a complex social phenomenon (Bury, 2000; Shakespeare, 2006; Shakespeare & Watson, 2001). Shakespeare (2006) has noted his

approval of the ICF definition of disability in part because it transcends what he sees as the limits of the impairment/disability dichotomy at the heart of the social model.

Impairment, it has been argued, is an essential part of the experience of being disabled, and it should not be ignored in disability studies (Crow, 1996; Morris, 1996; Shakespeare, 2006). In this construction, it is not possible to experience disability without having an impairment. It is argued that impairment plays a role in restricting the lives of people with impairment. As Abberley (2002) suggests, there will always be people who are excluded from mainstream social activities, such as performing paid work, because of the nature of their impairment. Thomas (1999), from a personal perspective, noted that there are many jobs that she would have trouble undertaking because of her impairment. Kittay (2001), for example, argued that, by definition, people with intellectual impairment will always require cognitive support.

The way in which impairment shapes the experience of people with impairment and excludes them from certain mainstream activities has led some commentators to question the usefulness of the social model altogether. Shakespeare (2006), for example, described a man with profound intellectual impairment and approved of the argument that “initiatives such as independent living, civil rights or barrier removal ... will not make a difference to his life, because his impairment is so limiting” (p. 60).

However, it is precisely assumptions such as this about the inevitability of social exclusion due to the severity of impairment that the originators of the social model sought to challenge. When Oliver wrote that disability has “nothing to do with the

body” (1996, p. 35), he underlined the social causes of disadvantage for people with physical impairment. He challenged the assumption that a person with a severe physical impairment could not expect to have the same opportunities as an able bodied person. Impairments are not all the same, and the needs of someone who has a spinal cord injury are different from those of a person with profound intellectual impairment. This is part of the complexity of disability that Shakespeare wanted to explain. Many social modellists, however, in contrast to Shakespeare (2006), would caution against assuming that barrier removal or civil rights are not relevant to people who have high support needs.

An example of this is offered by Zijlstra and Vlaskamp (2005), who found that people living in a residential setting were offered recreation for very few hours, of a limited sort, by professional staff only, and limited to within their residential unit. These restrictions in recreation opportunities were founded in social organisation rather than an intrinsic part of the recipients’ impairment. So although impairment may constrain the lives of people with impairment, the limitations of impairment, even for people with profound and multiple impairments, are not necessarily the root cause of barriers in their lives.

The initial promulgation of the social model has been caricatured as reflecting the concerns of men in wheelchairs, as Oliver (in Sheldon, Traustadottir, Beresford, Boxall, & Oliver, 2007) has acknowledged. Corker (1999) argued that the social model’s focus on restriction of activity reflects the concerns of people in wheelchairs rather than the concerns of people with other kinds of impairment that cannot be so readily described as resulting in barriers. Feminist writers too have noted that the

focus on getting paid work may reflect the interests of men of working age rather than those for whom paid work is less important, such as the young, the aged, those with profound and multiple impairments, or the parents of young children, especially mothers (Crow, 1996; Thomas, 1999).

Another criticism of the strong social model is that it gives insufficient ground to the role of individual agency within oppressive structures (Shakespeare, 1994), or, from another view, to the ways in which power is diffused (Tremain, 2005). Focusing only on disabling structures, it is argued, tends to homogenise the population of people with impairment, who are in fact diverse (Corker, 1999), and may ignore the ways in which those who are caught up in oppressive social relations are not passive recipients of oppression. Corker (1999; Corker & Shakespeare, 2002) extended her concern that the experience of disability varies with the nature of the impairment to consider also how disabling barriers vary between people with the same impairment, depending on their particular circumstances. Corker (1999) suggested that to lump together all people with a particular impairment as disabled is to risk losing the particularity of their situation. The importance of seeing social actors as active agents rather than victims of the structural constraints in which they live is a theme that has been taken up within the social model by writers such as Davis and Watson (2002).

The focus of the strong social model on the socially created nature of barriers to material wellbeing has also been criticised for giving insufficient attention to the impact of impairment and disability in the realm of cultural meaning. The understandings at stake here are to do with ubiquitous cultural messages about impairment as tragedy, deficiency, lack, incompetence, or aberrance, and with how

these ideas affect the identity of people with impairment (Abberley, 1987; Hughes, 2007; Shakespeare, 2006; Thomas, 1999; Watson, 2002).

The inability to perform particular tasks readily translates into the stereotype that people with impairment are incompetent, inferior, or less than normal in all tasks. As Sapey, Stewart and Donaldson (2005) noted, the competence of wheelchair users to perform physical and mental tasks apart from walking may also be called into question. Hughes (1999, p. 157) suggested that “to be impaired is to be perceived as invalid, to be seen as anomalous or contrary to order”. Abberley (2002) suggested that the understanding of impairment as inability and incompetence is an assault on the dignity and worth of people with impairment.

In the strong social model, negative attitudes towards people with impairment are understood as the product of particular social and economic circumstances, and therefore changing social attitudes is seen as secondary to changing the social circumstances that create such attitudes (Barnes, 1997). Oliver (1996), for example, certainly acknowledged the harm done to people with impairment by the idea of impairment as tragedy, which he saw as part of the individual model of disability. To change this, however, he was most concerned with removing barriers to social inclusion, rather than with changing attitudes per se.

Not all would feel confident that the negative cultural meanings of impairment will dissolve when people with impairment obtain equal access to social activities. Corker (1999) drew from the experience that negative attitudes towards women and ethnic minorities still persist in the face of social movements aimed at reducing their

oppression, to suggest that negative social attitudes towards people with impairment are not likely to be any less resistant to change. Shakespeare (1994, 2006) suggested that negative and prejudicial understandings of impairment and disability need to be understood as more than the by-product of unequal material opportunities for people with impairment. Therefore, he proposed that the process by which negative meanings of impairment and disability are generated and perpetuated was a legitimate and important area of engagement within the social model.

Despite these criticisms and concerns, the social model has been applied in many situations, including to women with impairment (Morris, 1996; Thomas, 1999; Wendell, 1997); to children with impairment (Davis & Watson, 2001; Priestley, 2000); to many types of impairment, including intellectual impairment (“learning difficulties” in the UK; Goodley, 2001); and outside high income countries (Priestley, 2001). The social model has provided a launching pad for theorising disadvantage for groups beyond the group of physically impaired working-age men who initially promulgated it. Whatever its failings in terms of the neglect of impairment, it has value because it sheds light on the social processes involved in causing disability for individuals, regardless of their impairment.

### Thomas’ social model

In her consideration of how disability is best understood, Thomas (1999) made a number of contributions to the debates outlined about the meaning of disability, the appropriate scope of the social model, and some failings in its original iteration. Thomas described what she calls the definitional puzzle of disability, pondering how it is that disability can be “nothing to do with the body”, as Oliver asserted, when

bodily impairment prevents the person from doing things, and disability can only occur in the context of having an impairment of the body or mind. Thomas (1999) agreed that impairment cannot be left only in the realm of the biological, because, as Abberley (1987) and others have argued, impairment has a social dimension. To counteract a biological-only or social-only approach, Thomas described impairment as profoundly biosocial. This recognition of the social dimension of impairment created a potential problem for the initial social model definition of disability. The problem is this: if disability is the socially created barriers that restrict what people with impairment can do, then on what basis can disability be distinguished from impairment, which also has a social dimension, and also creates barriers?

Thomas' (1999) solution to this question was to preserve the distinction between impairment and disability that is at the heart of the social model, but to tighten and clarify the definition of disability. She differentiated what she called the property definition of disability, which corresponds to the everyday meaning of disability as not being able to do something, from what she called the social relational meaning of disability, namely the barriers or restrictions experienced by people with impairment which arise out of the unequal social relationship between the impaired and the nonimpaired. Thomas suggested that the everyday meaning of disability found in the property definition is an inadequate starting point for empirical and theoretical study of disability, whereas the understanding of disability as a social relationship between the impaired and the nonimpaired provides a much stronger theoretical foundation. Thomas pointed out that confusion about the meaning of disability can arise when these two meanings of disability, the everyday property meaning and the social relational meaning, are used interchangeably.

Thomas' (1999) terminological solution is to reserve the term *disability* to mean only the barriers that are the result of the disabling, unequal social relationship between the impaired and the nonimpaired, and not to use the term more broadly to refer to having an impairment. Thomas theorised that both impairment and disability may cause disadvantage, but that the term disability should be reserved to mean the disadvantage that is wholly social in origin. Thomas termed the negative effects of impairment “*impairment effects*”, to distinguish them from disability proper. This term has been accepted and used by others from within the social model (Goodley & Tregaskis, 2006; Ryan, 2005; Smith & Sparkes, 2008). Thomas highlighted that impairment and disability are entwined in the lived experience of people with impairment, such that impairment effects can often be a marker for disability, and so it is often not possible to neatly separate the two. Despite the practical difficulty in pulling apart impairment effect and disability, Thomas argued that the distinction can and should be preserved because of its political significance.

Thomas (1999) used a personal example to illustrate how the disadvantage of impairment effects and disability although occurring together can be distinguished. She explained that because she does not have a left hand she is unable to do certain tasks, such as hold a spoon or a saucepan in her left hand. These restrictions are impairment effects. If, however, she is excluded from the role of mother or worker on the grounds of her impairment, not allowed to do things in an unconventional way to get around her impairment, or not given access to technologies that compensate for her impairment, then this is disability (Thomas, p. 43).

According to Thomas (1999), restrictions in social activity are caused by either impairment or disablism. Those caused by impairment are both biologically and socially determined, whereas those that are the result of disablism are wholly socially imposed. Thus, to identify disablism is not simply to notice that restrictions in social activities for people with impairment have a social component, but to identify the restrictions in social activity that are wholly socially created. Disablism is not necessarily indicated by the presence of a barrier to social activity, since that may also be caused by impairment. Disablism is indicated when the restriction in activity is wholly socially created and imposed (Thomas, 2004). Thomas highlighted the oppressive nature of the imposition of disabling social restrictions on people with impairment. She suggested that it is this oppressive quality of the relationship between the impaired and the nonimpaired that identifies the operation of disablism.

Thomas (1999) defined disablism as another form of social oppression akin to racism or sexism, while also acknowledging that the concept of oppression is not straightforward. She described it as “difficult to define”, because many issues are implied within it, including “issues of power imbalance, the systematization of privilege and underprivilege, the structural reproduction of inequality, the institutionalization of disadvantage” (p. 8). According to Thomas, disability is the disadvantage that is an outcome of an unequal and oppressive social relationship between two social groups, those with and those without impairment. It implies the operation of social power. She suggested that the scope of the social model is best described by maintaining the original insight of the UPIAS definition, that is, that a social relationship of inequality underpins the social restrictions of people with impairment. The idea of disablism as oppression implies that the nonimpaired enjoy

greater power, since they do not have to consider the circumstances and difficulties imposed by current social arrangements and cultural practices on people with impairment. Thomas' core questions regarding disability as oppression are: "How is the social relationship which constitutes disability generated and sustained within social systems and cultural formations, and why does it exist? How does this social relationship operate and manifest itself?" (p. 44).

Thomas (1999) pursued her questions by investigating women's experiences of living with impairment and disability. The experiences of the women who communicated with her provided Thomas with the window from which to view the sociostructural causes of disabling barriers in their lives. Consistent with other studies using the strong social model, Thomas described the ways in which the women with impairment experienced barriers to the material activities of life to do with housing, transport, work and leisure, and she argued that the women's reports of their daily lives reveal a great deal about contemporary social organisation for women with impairment.

She also used the women's experiences to argue for extension of the scope of the social model. She pointed to the harmful impact of negative cultural representations of impairment and disability on the women in her study. Following a feminist model, in which the personal is political, she argued that paying attention to personal experience is not a detour, but rather the road to uncovering political concerns. Thomas asserted that Oliver's (1996) private/public distinction actually impeded him from fully identifying the effects of disablism. For Thomas, the benefit of exploring the private lives of women with impairment was that the dimensions of disablism

were uncovered in personal relationships and self-esteem, areas which might otherwise be thought of as private and not relevant to the political concerns of the social model.

Thomas found that for the group of women whose stories she gathered, oppressive ideas about, for example, not measuring up to the ideal of feminine beauty were internalised and harmed them. She concluded that the harmful ideas the women held about impairment and disability came from the disabling attitudes, ideas, discourses and images that surrounded them. She summarised this as follows:

I want to consider dimensions of disability, of disablism, which tend to be obscured in the work of many social modellers because the emphasis has been on restrictions *of activity* and material disadvantage ... what has been obscured are the social barriers and limits to our psycho-emotional wellbeing, and to our sense of *who we are* and *who we can be*. (Thomas, 1999, pp. 44-45)

According to Thomas (1999), the undermining of psycho-emotional wellbeing constitutes another dimension of the barriers or restrictions of disablism, which she called barriers to being, to distinguish them from the more traditional barriers to doing that are the usual concern of the social model. Barriers to being seriously undermine and limit how people with impairment feel about themselves, and consequently how they act. Thomas gave the following as examples of the undermining of psycho-emotional wellbeing: “feeling ‘hurt’ by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, unattractive, hopeless, stressed or insecure” (p. 47). She suggested that negative ideas about impairment gain their power to seriously harm people with impairment when they are taken in and become an internal barrier to how one thinks and feels about oneself.

Thomas (1999) pointed out that for women with impairment to have a sense of their worth and attractiveness, they must resist and continually renew their resistance against ubiquitous negative ideas about themselves as women with impairment. The women's stories with which Thomas illustrated the harmful impact of negative ideas about impairment also show how women with impairment can, often after much effort, overcome ideas of their inadequacy and develop a sense of their worth.

Thomas focused on the harm that the internalising of negative ideas about impairment does to women as evidence of the non-material dimension of disablism. However, the harm of negative discourses, meanings, images and ideas about impairment seems to lie not only in the extent to which they undermine psycho-emotional wellbeing, but also in the work that women with impairment have to do to overcome the harmful effects of the negative meaning of impairment. The harm of the non-material dimension may lie not only in the amount of damage done to women. It may be that the process of having to deal with prejudice about impairment is a consequence of disablism, regardless of the degree to which psycho-emotional wellbeing is undermined.

In using the phrase "the socially engendered undermining of psycho-emotional wellbeing", Thomas (1999) emphasised that the problem lies not in the psychological adjustment of women with impairment but in wider social attitudes towards impairment. She maintained her focus on the social relational nature of disability by showing the connection between the inner state of people with impairment and how they are treated by nondisabled others. For Thomas, understanding the cause of this

social problem as arising from an oppressive relationship, is foundational to changing prejudicial and exclusionary understandings of impairment and disability.

Thomas (1999) gave equal prominence to her construct of barriers to being along with the barriers to doing traditionally associated with the social model of disability. She pointed out that the lives of the disabled adult women who participated in her study were restricted by negative ideas about impairment and disability just as surely as a flight of stairs restricts a person in a wheelchair. She argued that the strong concern in the social model about material disadvantage for people with impairment is quite compatible with a concern about non-material disadvantage, such as the impact of negative and prejudicial meanings of impairment on personal identity.

The relationship between material and non-material disadvantage is a challenge for social theorists of all persuasions, and has been a topic of debate within the social model (Priestley, 1998; Shakespeare, 1994; Thomas, 2002). Thomas' definition of disability refers to the materialist understanding of power as arising from socioeconomic structures and conditions. Much earlier, Abberley (1987) had suggested that the negative beliefs about people with impairment and aligned disadvantage benefit other groups in society. It may be that ideas about the tragedy of impairment persist at least in part because they save the nondisabled group the obligation to consider and improve the situation of people with impairment, and they allow the time, effort, and money that would be required to make such change to be used for other purposes. Thomas' conceptualisation of the distinction between impairment and disability opens up space within the social model for a discussion of social as well as cultural and ideological questions.

Thomas (1999) argued that it is possible to maintain the original UPIAS meaning of disability as socially imposed disadvantage distinct from impairment, and so maintain the political and ethical agenda of the social model, while strengthening the epistemological foundations by acknowledging the part impairment plays. In her formulation, she responds to the major criticisms that have been levelled at the social model as follows: impairment as well as disability can restrict people with impairment; individuals retain agency and need to combat social structure; and cultural representations of impairment and disability have an impact and may also create disabling barriers.

## Conclusion

This chapter outlined the origins of the social model of disability, and challenges to this model. Thomas' response to criticisms of the original social model was to take the definition of disability beyond the concept of activity restrictions and to embed activity restrictions within the relationship of disablism. Thomas identified that the relationship of disablism is manifested in both material and non-material dimensions. Thomas' work is significant for the current study because her understanding of disablism came from paying attention to women's experiences. This consideration of the material and non-material impact of disablism, derived from women's day-to-day experiences, offers a useful approach to explore the daily life experiences of families of children with impairment.

Before considering the potential value of applying this approach to the experience of families, it is first necessary to review the considerable literature on families with a

child with impairment, which up until now has not used a social model perspective. This literature exposes the disadvantage experienced by families with a child with impairment. Literature on the social model, on the other hand, has little to say about the situation of families. In the next chapter I consider first the situation of families, then move on to Thomas' understanding of disablism, and her method for exploring it, as a way forward to explore the experience of families with children with impairment.

## *Chapter 3*

### *Families with children with impairment*

#### Introduction

This thesis is concerned with the usefulness of the social model of disability in understanding whether disablism occurs in the everyday lives of families who care for a child with impairment. The previous chapter introduced the social model, its theoretical development and the success of its application to individuals with impairment. Before considering its application to families, however, I review some of the considerable literature on families with a child with impairment. Broadly speaking, this literature does not include a social model perspective. The extensive literature about families with children with impairment provides evidence of disadvantage. The literature reviewed in this chapter is only one part of the more extensive literature on families with a child with impairment. In my review, I identify studies which document areas of disadvantage for families, and then propose what the social model in theory and in practice brings to understanding such family disadvantage. I argue that the potential of the social model to understand disadvantage for families with a child with impairment remains largely unexplored. This then sets the stage for my study of the relevance of the concept of disablism in family life for families with children with impairment.

## Approaches to understanding family experiences

### *A historical perspective*

The lens through which families with a child with impairment have been viewed has changed over time. Ferguson (2001) identified three periods in research about families with a child with impairment. The first trend occurred in the period from the early to mid-twentieth century, in which families remained in the background of impairment research. The second period was from the 1950s to the 1980s, when research into families with a child with impairment increased. In this period, research could be characterised as documenting the extent to which the family is harmed by having a child with impairment. The third is the period from the 1980s to the present, in which the consequences for families of having a child with impairment are recognised as dependent on the context, including the adequacy of services, in which the family raises the child. Ferguson suggested that in this third phase, the positive as well as negative consequences for families of having a child with impairment are now recognised.

According to Ferguson (2001), families were of little interest in the first early period, because at that time most concern was directed at curing the impairment. Later however, after the Second World War, interest in families with a child with impairment burgeoned. In this new phase of research the presence of a child with impairment was thought to be harmful for the family. One of the dominant ways of understanding human behaviour at that time was psychoanalytic thinking. Not surprisingly therefore, families of children with impairment were described as responding with neurotic emotions such as denial, guilt and resentment to the trauma of having a “defective child” (Solnit & Stark, 1961). Mothers received particular

attention. They were thought to be damaged in that they had to mourn the loss of the imagined, wished-for “normal” child. It was also thought that the mourning process was made more damaging for mothers because “the daily impact of the retarded child on the mother is unrelenting” (Solnit & Stark, p. 533).

A related view at this time was that parents with children with impairment experience “chronic sorrow” (Olshansky, 1962). That is, parents experience an ongoing sadness that is continually renewed by regular reminders of their child’s incapacities. Rather than being a neurotic reaction, chronic sorrow was conceptualised as a normal reaction to the tragedy of impairment. As Olshansky noted, parent sorrow is the “natural response to a tragic fact” (p. 193), and if, on occasion, a parent denies the “reality of the child’s defectiveness” (p. 191), this is because denial “may help the parent to tolerate better the terrible reality that confronts him each day” (p. 191). The tragedy is elaborated by Olshansky as the child’s unending dependence, and the burden this places on parents:

The parents of a normal child have to endure many woes, many trials, and many moments of despair. Almost all these parents know, however, that ultimately the child will become a self-sufficient adult. By contrast, the parents of a mentally defective child have little to look forward to; they will always be burdened by the child’s unrelenting demands and unabated dependency. The woes, the trials, the moments of despair will continue until either their own deaths or the child’s death...Release from his chronic sorrow may be obtainable only through death. (pp. 191-192)

From this chronic sorrow perspective, tragedy is intrinsic to impairment. Despite a lack of empirical support (Stoneman, 1997), the concept of chronic sorrow continues to be used to describe the response of families to having a child with impairment (Nieto & Roach, 1997; Bruce & Schultz, 2002). Summers, Behr, and Turnbull (1989) suggest that the concept of chronic sorrow has an enduring appeal because it accords

with the popular belief that having a child with impairment must be a tragedy. However, according to Ferguson (2001), the notion of chronic sorrow has been largely superseded. The dominant research paradigm in the third and current period is that of family stress.

#### *The state of current research*

The family stress paradigm does not assume that families with children with impairment necessarily experience stress, but that the confluence of a variety of factors within and external to the family leads to stress which is experienced differentially across families (Crnic, Friedrich, & Greenberg, 1983; McCubbin & Patterson, 1983). Family stress has become the variable of interest to be measured and its relationship with other variables explored. Stoneman organised her 1997 review of the literature on families around the areas of family life that had been investigated as potentially causing family stress, and the topic headings of the review give some hint of the scope of the research effort at that time. These include: child characteristics, child transitions, difficulties relating to parenting the child with impairment, amount and types of social support available to families, social support differences between mothers and fathers, developmental changes in social support, siblings as a source of support, service support, coping strategies and their effectiveness, coping differences between mothers and fathers, marital quality, effects on siblings, social context effects, work role changes, grief and sorrow, and hardiness.

Although the concept of family stress originated in the psychological literature, according to Ferguson and others (e.g. Bailey, 2007; Hatton & Emerson, 2003), current research is characterised by a greater focus on the social context of families with a child with impairment, and the social response *to* the family, rather than

focusing entirely on the psychological response *of* the family. Ferguson (2001) has noted that much of the research on family stress gives some pride of place to contextual factors, and does not conceptualise family stress to be caused solely by impairment. However, this trend does not equate to a complete break with the concept that family stress is caused by the presence of impairment. According to Hatton and Emerson (2003), the theoretical models upon which family research is based continue to be dominated by a psychological framework. The impact on the mother of having a child with impairment continues to be a dominant theme because it is used as an indicator of the wellbeing of the family. Their view is that although the environment in which the family brings up the child is acknowledged as a potential cause of family stress, it is not conceptualised as central to family stress or as its primary cause. Agreeing with this view, Blacher, Neece, and Paczkowski (2005) suggest that the negative impact on families of having a child with impairment remains a dominant theme. Nevertheless, the family stress literature identifies areas of disadvantage for families with children with impairment. I now outline evidence of family disadvantage, because evidence of family disadvantage provides a starting point from which to explore the potential applicability of the social model to the situation of families with children with impairment.

## Evidence of family disadvantage

### *The wellbeing of mothers*

One of the most well documented research findings of family disadvantage is that mothers of children with impairment are more likely to experience lower levels of emotional wellbeing than other mothers (Blacher & Baker, 2002; Blacher, Neece, &

Paczkowski, 2005; Eisenhower, Baker, & Blacher, 2005; Emerson, Robertson, & Wood, 2004; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). For example, a recent Australian report found that the wellbeing of primary carers of children with impairment was lower than that of primary carers without children with impairment and that carers of children with impairment had less social contact than other parents (AIHW, 2004). A recent Australian study by McConnell and Llewellyn (2006) surveyed the mental health of a group of 74 mothers caring for school-aged children with impairment. These authors found that the mothers, despite enjoying relative social advantage in terms of income and education, reported low levels of emotional wellbeing as measured by a standardised and validated measure of emotional health. Another recent Australian survey of the wellbeing of carers (not restricted to parents of children with impairment) found that carers were much more likely to be depressed than others in the population (Cummins et al., 2007). In that study, 56% of carers surveyed scored in the moderately depressed range on a questionnaire measure of depression, compared with 6% of the general population, and the general wellbeing of carers (a composite measure of self-reported health, relationships, safety and community involvement) was reported as low. Such surveys rely on recruiting participants from the services they use, and it is problematic to generalise the findings of such studies because the characteristics of the particular population of parents that are sampled may differ from the population of parents with children with impairment as a whole. For example, parents who are recruited into studies via services may differ from parents who do not use services.

In a series of recent papers, Emerson and colleagues (Emerson, 2003; Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006; Emerson & Llewellyn, 2008; Emerson,

Robertson, & Wood, 2004, 2007) used a different sampling method to investigate the emotional health of mothers with children with impairment. Emerson and his colleagues analysed data from large scale, population-based studies. The use of such data allows a more authoritative comparison to be made between the groups of mothers with and without children with intellectual impairment than those studies that use service-based samples. Overall, the findings of these studies highlight the importance of socioeconomic position in influencing mothers' wellbeing in families with children with impairment. They suggest therefore that poverty needs to be conceptualised as an important correlate of family stress.

For example, Emerson (2003) showed that the relatively lower wellbeing of mothers of children with impairment that has been so often observed in families with children with impairment may be more attributable to socioeconomic position than to the presence of a child with impairment per se. Emerson found that mothers of children with intellectual impairment experienced considerable psychological distress and social disruption but that, other things (in particular, economic disadvantage and child behaviour problems) being equal, mothers with a child with intellectual impairment were in fact *less* likely to report mental distress than other mothers. In a later study using data from another large and representative UK sample, Emerson et al. (2006) confirmed the higher levels of psychological distress for mothers with children with intellectual impairment, and that this higher rate of emotional distress varied with socioeconomic disadvantage.

In Australia, the recent study by Emerson and Llewellyn (2008) using data from a large and representative population-based sample examined the level of emotional

wellbeing of the mothers of children at risk of developmental delay. The study found that the level of wellbeing reported by these mothers was lower than that of other mothers. Consistent with results from other studies by Emerson and colleagues using UK data, Emerson and Llewellyn also found that the level of distress of mothers with a child at risk of developmental delay was strongly associated with economic position. Their findings suggest that although mothers of children with impairment reported lower levels of emotional wellbeing than their peers, they were also more likely to experience poverty, and that about half of the extra distress experienced by mothers of children at risk of developmental delay could be accounted for by their lower socioeconomic position. Emerson and Llewellyn suggested that their data provide further evidence that the well-known link between socioeconomic position and health (Marmot & Wilkinson, 2006) also applies to the mental health of mothers in families with children with impairment. Taken together, the studies of Emerson and his colleagues illustrate that the wellbeing of families with children with impairment depends on the social context in which families bring up their children with impairment.

### *Financial disadvantage*

Financial disadvantage of adults with impairment was one of the drivers of the social model (Barnes et al., 2002; Oliver, 1996). Many studies since have shown a correlation between impairment in adulthood and poverty (e.g. Apospori & Millar, 2003; Saunders, 2006) As I described earlier in regard to the emotional wellbeing of mothers, there is considerable evidence that the association between poverty and impairment also holds for families of children with impairment (see also Birenbaum, 2002; Oliver, 1998). Families with children with impairment as a group are financially disadvantaged on a number of indicators of financial disadvantage

(Emerson & Hatton, 2007). Children with impairment are more likely to live in low income households (Emerson, 2004; Emerson & Hatton, 2007; Fujiura & Yamaki, 2000). Emerson (2003) gave an example of the magnitude of the income inequality between families with and without children with impairment when he reported that in a large UK population-based sample 44% of children with intellectual impairment aged from 5 to 15 lived in poverty, compared with 30% of nondisabled children. Emerson and Llewellyn (2008) reported that in Australia, again based on a large and representative sample, 46% of children at risk of developmental delay were living in poverty, compared with 24% of children not identified as at risk of developmental delay.

The extra expenses that families incur in raising a child with impairment contribute to their economic disadvantage relative to their peers. Family income may be reduced because of impairment-related expenses, such as cost of special equipment, therapies, medical appointments and travel (Dobson, Middleton, & Beardsworth, 2001). These impairment-related expenses may push families who are already struggling into financial hardship. The cause of the relationship between family poverty and having a child with impairment may not be found simply in the greater financial costs imposed by impairment on families, because poor families are more likely to have a child with impairment in the first place (Anderson, Dumont, Jacobs, & Azzaria, 2007; Leonard & Wen, 2002). This may be at least in part because children in poor families have higher rates of low birth weight and higher rates of adverse experiences, factors which are linked with impairment (Birenbaum, 2002; Emerson & Hatton, 2007). Poor families are also more likely to live in neighbourhoods that are detrimental to child development (Emerson, 2004; Graham, 2005).

The time demands of caring for a child with impairment mean that many mothers are less available to participate in the paid workforce (Bittman, Fast, Fisher, & Cathy, 2004; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Parish, 2006). The income forgone by mothers is a financial opportunity cost for the family as a whole and is a likely cause of some of the financial disadvantage families with children with impairment experience. One US study prospectively compared family savings and income over time between families with and without children with impairment, and found that families with a child with impairment had lower savings and income by midlife, even though parents in the families had started off from similar socioeconomic positions in early adulthood (Parish, Seltzer, Greenberg, & Floyd, 2004). This study also indicated that mothers of children with impairment increased their employment hours more slowly, were less likely to work full time, and less likely to have worked for 5 or more years uninterrupted. The authors concluded that this financial disadvantage for families with children with impairment is due to the combined costs of out-of-pocket expenses of impairment and the income mothers forgo due to caring responsibilities.

### *Maternal employment*

Mothers of children with impairment are less likely to do paid work than other mothers (AIHW, 2004; Beresford, Sloper, Baldwin, & Newman, 1996; Dobson et al., 2001; Einam & Cuskelly, 2002; Gordon, Rosenman, & Cuskelly, 2007; Olsson & Hwang, 2006), or are employed part-time and therefore in lower paid jobs that have less of a career path (Knox, Parmenter, Atkinson, & Yazbeck, 2000; Parish, 2006; Warfield, 2001), and for shorter lengths of time (Parish et al., 2004).

Even in a country such as Sweden, where it is the norm for mothers to do paid work and where there is considerable support for them to do so, the workforce participation of women with children with intellectual impairment is lower than that of other women (Olsson & Hwang, 2003). Olsson and Hwang report that when asked why they were less available to do paid work, mothers with a child with intellectual impairment gave a number of reasons: the demands of caring for their child made them tired; they were unable to find suitable child care; the child's needs made it difficult for them to be flexible at work; they needed to be absent from work to take the child to appointments or because the child was sick; or they preferred to be at home with the child.

Mothers may prefer to be at home with their child rather than doing paid work, whether or not their child has an impairment, and there may be stages in the life of a child with impairment where the mother prefers to be with the child rather than in the paid workforce (Cuskelly, Pulman, & Hayes, 1998). However, it is important to note that the differences in workforce participation between women with children with impairment and typically developing children do not simply reflect the preference of mothers with children with impairment to stay at home to care for their children.

When Gordon et al. (2007) analysed the level of workforce participation of mothers with and without children with impairment, using a large and representative sample in Australia, they found that mothers with children with impairment were less likely to work, or worked for fewer hours, than other mothers. Mothers of children with severe impairment in particular were less likely to do paid work. At the same time, however, Gordon et al. found that mothers of children with impairment were no less desirous of paid work than other mothers. They concluded that the differential work patterns of

these two groups of mothers, in Australia at least, could not be attributed to the mothers of children with impairment simply not wanting to work.

Qualitative studies in the US and the UK also provide evidence that women with children with impairment want to work, and why this might be. In the US, Parish (2006) conducted focus group interviews with eight mothers of adolescents with developmental disabilities, to examine how these mothers managed employment and caregiving. Parish found that the balance between work and caring responsibilities was hard for these mothers to achieve, and that a particular issue for mothers of adolescent children with impairment was the lack of child care services for children of this age. She reported that the mothers with whom she spoke valued paid work, and that they wanted to work even when they had to battle to start or keep working. Shearn and Todd (2000) found similar attitudes towards employment in a group of 18 Welsh mothers of school-age children with intellectual impairment. These authors reported that the mothers in the study valued employment because they saw it as an opportunity to escape from isolation and peripherality, and consequently many mothers regretted their inability to do paid work. In a later study based on interviews with a different group of 30 mothers of adolescents with intellectual impairment, Todd and Jones (2003) reported that the mothers they spoke to did not always voice their preferences, such as a wish to work, for fear that they might be seen by professionals as putting their needs as a mother ahead of their children. It may be that the restriction on paid work is a disadvantage for those women who regret their inability to work, but that this disadvantage is downplayed when women are reluctant to voice their dissatisfaction.

Not being able to do paid work may harm women in many ways. Perhaps the most important negative consequence for mothers of children with impairment is the loss of income for the mother and family. This makes mothers and their families more vulnerable to the multiple harmful impacts of poverty (Marmot & Wilkinson, 2006). The paid work role can protect mothers from the negative impacts that are associated with caring, such as social isolation (Shearn & Todd, 2000) and depression (Einam & Cuskelly, 2002).

There is also some evidence that despite the potential loss of paid work identity, mothers of children with impairment can simultaneously experience fulfilment in their identity as “special” mothers. They may gain a specialist identity as a result of their unpaid work that is rewarding because of their expanded personal boundaries and expertise (Todd & Jones, 2005; Traustadottir, 1991). When this is the case, the disadvantage of missing out on paid work may be mitigated or overcome by the enhancement to identity of having a special status. However, the extent to which mothers are able to gain from this potential for a special identity as mothers of children with impairment may depend on their socioeconomic and cultural circumstances. Eisenhower and Blacher (2006), for example, explored the extent to which mothers of young adults with intellectual impairment from both majority (Anglo) and minority (Latino) culture in the US were able to benefit from or were challenged by the demands of managing the roles of carer, spouse, and worker. They recruited 109 Anglo mothers and 117 Latina mothers through services. They found that work and marriage exerted complex effects on carers but that overall, mothers most at risk of poor mental and physical health were those who only had one social role, that is, mothers who were unmarried and not working had the lowest levels of

wellbeing. They concluded, supporting the findings of Emerson and colleagues, that socioeconomic status mediates maternal wellbeing. It could be that those who are most able to experience the potential gain in identity of being a “special” mother when they are not able to be paid workers are those who can most afford to forsake the income and status of paid work because they already enjoy a relative economically privileged position.

### *Family leisure*

There is some evidence that families with children with impairment experience differences in their leisure opportunities compared with other families, and these differences might also be evidence of disadvantage. Caring for a child with impairment often places more extensive time demands on parents than caring for a typical child (Shearn & Todd, 2000). Bittman et al. (2004, p. 76) described the Australian carer’s pattern of time use as marked by “a substantially lower rate of participation in the labour market and in education, increased time spent in domestic work activities and, in the case of caregivers of children, the time spent in direct childcare”. Time spent in care activities reduces the time that carers have for leisure: “much of the care time appears to be subtracted from the time available for paid work and leisure” (Bittman et al., 2004, p. 84). Although the impact of caring responsibilities on mothers’ participation in the paid workforce has received some attention, the impact of caring responsibilities on family leisure has rarely been explored (Mactavish & Schleien, 2004).

Parents report their concern that their caring responsibilities have a negative impact on their personal leisure time (Hornby, 1995) and on the time they have available for their other children (Blyth & Gardner, 2007; Olsson & Hwang, 2003; Swenson,

2005), although siblings of the child with impairment do not always share this concern (Guite, Lobato, Kao, & Plante, 2004). Recreation opportunities for individuals with intellectual impairment are restricted (Schleien, Ray, & Green, 1997; Zijlstra & Vlaskamp, 2005), and this may also affect other family members. Parents may feel a responsibility to compensate their child with impairment for reduced recreation opportunities (Mactavish & Schleien, 2004). When children are unable to access certain recreation options because of the nature of their impairment, this restricts what their parents can do (Ryan, 2005). For example, getting out of the house can be a major operation for families whose children have complex medical needs (Yantzi, Rosenberg, & McKeever, 2006).

Parents often report their concern that their caring responsibilities have a negative impact on the family's social life. Olsson and Hwang (2003) surveyed 226 families with children with intellectual impairment ranging in age from 0 to 16, and compared their responses to those of a control group. Families with children with intellectual impairment reported that they had fewer recreation options than other families because it was hard to find a suitable babysitter or to find activities that the whole family could do together. Families of children with impairment also reported that their options for suitable holidays were restricted.

The nature and benefits of family recreation with children with impairment were explored by Mactavish and Schleien (2004), who analysed questionnaire responses of a group of 65 parents of children with impairment ranging in age from 2 to 22, and then conducted interviews with 16 of these parents. Like Olsson and Hwang (2003), they reported that finding a suitable activity for the whole family to engage in was

challenging for families. Mactavish and Schleien found that parents of children with impairment valued recreation as a family, and that they therefore sought activities in which children of varying ages and skill levels could participate together. This could be more difficult to find when a child has an impairment. Children with impairment may also be included in family recreation at an age when children typically do activities without their parents. Mactavish and Schleien also reported that families had to balance conflicting interests and timetables in order to find common ground when organising family recreation, and suggested that the needs of the child with impairment may make this a more complex task for families.

Todd and Jones (2005) also reported how families with children with impairment viewed their family leisure opportunities. These authors analysed interviews conducted with mothers of adolescent children with impairment from the perspective of the life stage of the mothers. From this perspective, they identified that differences in the lifestyles of families with children with impairment were becoming more evident at this stage of the family's life cycle. They suggested that these differences were seen by parents as disadvantages when, due to contracting formal support from services and informal support from other children, family life was seen as inflexible and social opportunities were seen as restricted.

### *Services*

Families with children with impairment typically have involvement with health, welfare, and educational services. This is not in itself a disadvantage, in that these services aim to help the child with impairment and their family. These services typically claim that their philosophy is one of family-centred care, based on the ecological model in which the family is conceptualised as best placed to influence the

child's impairment, and on the parents' wish to be involved with their child's care (Leiter, 2004). There is a considerable literature on what constitutes quality in early intervention services, for example, in which two factors are consistently associated with parent satisfaction with services. These two aspects of service delivery are a listening, compassionate style of relating with parents and an individual and responsive approach (Dunst, Trivette, & Hamby, 2007).

Despite this knowledge about what constitutes a good service in the eyes of parents, and the considerable agreement between parents and professionals about the desirability of family-centred practice, parents frequently report dissatisfaction with services (e.g. Case, 2000; Keen, 2007). Parents give a number of reasons for their dissatisfaction. Difficulties for parents in negotiating the complexities of service systems are often reported (Knox et al. 2000; Olsson & Hwang, 2003; Read, 2000; Redmond & Richardson, 2003). Parents report that there are not enough services and that services are hard to access. Olsson and Hwang (2003), in their survey of a group of 226 Swedish parents with children with intellectual impairment, found that most parents were satisfied with the services they received, but that even in a country that provides considerable support to families with children with intellectual impairment, a number of parents still commented on the difficulty in finding the services that they needed. Parents of school-aged children often describe difficulty obtaining before- and after-school care or school holiday care (e.g. Dowling & Dolan, 2001; Parish, 2006). For example, a parent reported that being able to obtain only four days of school holiday care over the course of a year for a child with impairment (Dowling & Dolan, p. 31). Parents report that dealing with services can be time consuming (Beresford et al., 1996; Olsson & Hwang, 2003) and frustrating (Beresford et al.,

1996; Dowling & Dolan, 2001; Knox et al., 2000). Knox et al., who sought the opinion of 68 families with children with impairment regarding services in a growth area on the outskirts of Sydney, Australia, noted that many parents felt that services were insufficient, and that this “fostered an atmosphere of lack of control, of exasperation and helplessness” (p. 23).

Several authors report that the delivery and organisation of services is often inflexible, so that parents feel that what is provided is determined by what services have to offer rather than what parents would like them to offer (Dowling & Dolan, 2001; Redmond & Richardson, 2003; Yantzi et al., 2006). Parents may feel that they have to fit in with the requirements of services, even though the service timetable does not match the family’s preferences. For example, Einam and Cuskelly (2002) reported that the hours of a day program did not necessarily suit other family members, as evidenced when a parent had to be home when a young adult child finished a day program in the early afternoon. The hours of this program were given to parents as a *fait accompli*, rather than negotiated with families.

Parents may feel that changes to programs are made without consulting them (Caldwell, 2007). Parents spend time seeking out and organising services. They may also have to reapply for services that they have previously received. Service provision may be inconsistent, because services can be reduced or cut regardless of the family’s circumstances. Parents may therefore be uncertain as to whether they will continue to be eligible to receive services, and services are not experienced as an entitlement. When services are inconsistent, families can feel that their situation is unstable or even precarious. In their study of the experiences of mothers in the middle years of

parenting, when children are adolescents, Todd and Jones (2005) reported that parents were challenged by changes and uncertainties in the services that they accessed, at the same time as they were more likely to face reduced informal support. Schneider, Wedgwood, Llewellyn, and McConnell (2006) similarly commented on the impact of service discontinuity and uncertainty on family life. These authors analysed descriptions of family life of 20 families with children with impairment aged 10-21, and described families as advocating for services for their child with impairment and co-ordinating the services that their child received. They described a number of families as having to forgo a valued part of their family life in order to care for their child with impairment, a loss that parents felt unable to persuade services to help them avoid.

Because it is mothers who are typically the primary carers for children with impairment (e.g. AIHW, 2004), mothers usually have the responsibility for negotiating with services. Mothers can feel disparaged by the services with which they spend considerable time interacting. This is evident in the analysis given by Todd and Jones (2003) of the lives of mothers of adolescents with intellectual impairment. Todd and Jones interviewed 30 mothers, and found that relationships with service providers were often described, and often negatively, by these mothers. In particular, they reported that mothers felt that they were being stereotyped as neurotic or fussy, or even blamed for their child's difficulties by service providers. These authors described the mothers as feeling that their competence and worth as mothers was under scrutiny from service providers. Allied with this perception was mothers' sense of not feeling understood by and not feeling able to trust service providers. Goodley and Tregaskis (2006) also commented on the potential for professional power and

expert knowledge to have a negative impact on parents. These authors interviewed parents of younger children, aged 4 or 5, to obtain their accounts of the care that their child had received, and from these descriptions identified enabling care from the parents' perspective. From the accounts of five of the parents interviewed, they argued that the positioning of professionals as experts and conveyors of certainty about children with impairment risked overlooking the expertise of parents in understanding and caring for their child with impairment.

An unequal power relationship underlies many of the reported difficulties in the relationship between families and services. Many of the negative feelings that parents have reported in their dealings with services, such as feelings of powerlessness and lack of reciprocity or genuine partnership, are underpinned by this power imbalance. Read (1991) noted that mothers felt their relationship with service providers was precarious because the mothers had little sense of control or choice in an area of their life that was very important to them, and that this was due to an imbalance of power. Knox et al. (2000) described the families in their study as being obliged to interact with service providers even when the service providers were not competent, and commented that for these participants the "sense of powerlessness...was palpable" (p. 24).

### *Stereotyping and stigma*

So far, I have considered the material activities of life in which families participate, and the evidence that families with a child with impairment experience disadvantage in these activities. Disadvantage may also be experienced in less material spheres of family life, such as how one is understood by others. Being a member of a minority group, such as being a family with a child with impairment, is not necessarily a

disadvantage. Minority group membership becomes a disadvantage when variation from dominant group norms is constructed as deviant and abnormal, and when the subordinate group is viewed in stereotypical ways. Stereotypes then have the power to harm the minority group (Young, 1990). Stereotypes can be used by the dominant group to explain every part of the life of the person who is marked as different from the majority (Young, 1990).

For people with impairment, the harmful impact of stereotype that Young describes as a feature of oppression is evident in the phenomenon of “identity spread” (Shakespeare, 2006). For example, Sapey et al. (2005) examined the willingness of wheelchair users to identify as disabled. They described the person in a wheelchair as stereotyped as not just unable to walk, but as generally incapable. This is identity spread. This phenomenon can also operate in families. Todd and Jones (2003), for example, described how mothers of children with intellectual impairment struggled to have their view of themselves and their families as ordinary confirmed by professionals. Shearn and Todd (2000) also described how some mothers of children with impairment faced a particular challenge in being seen by others as a person in their own right rather than as a mother to a child with impairment. Todd and Jones (2005) also suggested that mothers with children with impairment resist an identity as “special” parents because it threatens to overshadow the rest of their identity.

The devaluing of people with impairment can affect their family members and associates. Parents may take on socially derived guilt and blame for “failing to successfully reproduce” (Avery, 2002; Landsman, 1998). When dominant norms call into question the personhood of the person with impairment (Landsman, 2005),

especially for those with intellectual impairment (Parmenter, 2001), this may also affect family members. Goffman (1963) used the term “courtesy stigma” to describe the spread of stigma from the stigmatised person to those close to them. For children with impairment, stigma can extend to their families (Birenbaum, 1992; Green, Davis, Karshmer, Marsh, & Straight, 2005). According to Gray (1993), parents of children with autism can see themselves as stigmatised by their child’s “disorder”. Green et al. (2005) described stigma as a relationship between the stigmatiser and the stigmatised, with stigma being experienced vicariously by mothers of children with impairment. These authors reported that the interviews they conducted with seven mothers of children with varying impairments from preschool to high school age revealed that mothers too experienced stigma. They also reported that stigma was most damaging when it occurred in the context of an unequal power relationship.

The status of the family as a normal family may be in question when they have a child with impairment, because they do not conform to normative ideas of family (Silverman, 2005). McKeever and Miller (2004) suggested that mothers of young children with impairment are themselves marginalised and stigmatised along with their children. These authors analysed interviews with Canadian mothers of children with impairment, and reported that the need to overcome the devaluing by stigma underpinned the work that the mothers did to present their child and themselves as capable, co-operative or dignified to others in the fields of medical care and education.

Community acceptance of antenatal screening and the selective abortion of children with genetic “abnormality” foster prejudice against impairment (Shakespeare, 2006).

Lenhard et al. (2007) also suggest that the existence of antenatal screening programs may have increased the burden on mothers of children with impairment. They compared the perceptions of mothers of children with impairment about their reception in the community before and after the introduction of antenatal screening, administering a questionnaire to parents of children with impairment in the same area of Germany 30 years apart. At the time of the first questionnaire, in 1970, antenatal screening had not yet been introduced. At the time of the second questionnaire the mothers felt that they received more respect and esteem from other parents of children with impairment than did mothers at the time of the first questionnaire, but at the same time the second cohort of mothers also felt more blamed and excluded by the community at large. The authors attributed this increase in mothers' perception of exclusion to the introduction of antenatal screening, although it is possible that other social changes in the time between the two questionnaires could have contributed to this result.

### Towards a social model perspective on family disadvantage

A body of evidence about the situation of families who have a child with impairment suggests that these families experience disadvantage compared with families without children with impairment, in the areas of family income and socioeconomic position, maternal paid work opportunities, maternal wellbeing, and family leisure activities. Families may experience difficulties in their relationship with services, and families may also be seen in stereotyped ways.

The evidence of family disadvantage outlined above comes from research studies that with a few exceptions have not used a social model framework. The disadvantage in

material and non-material circumstances that families with a child with impairment experience has been understood largely as a consequence of having a child with impairment. There is now some evidence, however, to suggest that the cause of this family disadvantage is not wholly the presence of impairment. Family poverty, for example, has been correlated with poor maternal wellbeing (Emerson, 2003).

The social model argues that the disadvantage experienced by individuals with impairment is disablism, that is, a process by which social structures and practices fail to take into account the needs of individuals with impairment, and which results in socially created barriers in their lives. The challenge taken up in this thesis is to discern whether disablism can also be applied to understanding the situation of families with a child with impairment.

The history of the social model as described in Chapter 1 comes from a political agenda to benefit the individual with impairment. Oliver (1996), for example, acknowledged that disability also affects the family members of individuals who are disabled, but described the efforts by the nonimpaired to assist the impaired as essentially misguided and ineffective. There is, however, more than one study which has used the social model to understand the position of families with a child with impairment.

Dowling and Dolan (2001) explicitly advanced the argument that such families are disabled along with their children. This study is based on interviews with 22 parents of children aged 0 to 18, as well as with children and service providers, who were recruited as users or potential users of respite care services in a particular area of

England. Dowling and Dolan (2001) argued that families experienced “unequal opportunities and outcomes – in work, leisure, finance and quality of family life” (p. 24) that were evidence of disablism in family life. In sum, the authors argued that family disadvantage was not the result of impairment, and that families were disabled by lack of funding, inflexible care arrangements and the prejudiced responses of others.

Dowling and Dolan (2001) furthermore reported that families with children with impairment experienced disadvantage in a range of areas of family life. Services received particular attention. The authors described the process of applying for services as “long, slow, time consuming, complicated and the source of intense anxiety and frustration” (p. 26). Having to apply and reapply for services and to struggle and wait for services was reported to harm carer wellbeing and family quality of life. The way that services were provided was also criticised as inconvenient and exhausting, because they were not provided locally or at venues convenient to parents. Services were found to be wanting in flexibility and responsiveness, for example in not allowing siblings to go to respite care, and in not sufficiently consulting families in service planning and provision.

Dowling and Dolan (2001) also observed that caring for a child with impairment could harm the mental health of carers. They linked this to what they saw as a “sense of isolation for the disabled child and the parents” (p. 30). They further argued that the exclusion that results in isolation for children and their carers is not inherent to impairment and is “social in nature”. Dowling and Dolan also found that family members could miss out on experiences that other families could expect to enjoy.

They asserted that the cause of this negative outcome for the family was social in origin, and not the impairment. For example, they quoted the case of one family in which no one went to the cinema: “His parents had reached the point where they were no longer able to face public disapproval of the disruption that Philip may cause if disturbed by anything. Public intolerance meant that the whole family missed out” (p. 31). They also found that mothers faced barriers in doing paid work because of caring responsibilities and a lack of school holiday care.

Dowling and Dolan (2001) argued that all these disadvantages for families with children with impairment were evidence of inferior opportunities and outcomes for families, which were not inherent in their child’s impairment, and that families were therefore disabled. (They used the term disability, not disablism.) However, the theoretical approach for this study has some shortcomings. Firstly, differences in family life between families with a child with impairment and other families were interpreted as necessarily disadvantage, as for example when the authors asserted that going to numerous specialist disability appointments, which mark the life of the family with a child with impairment as different from other families, must harm family wellbeing. They also assumed that any restriction in family life must be evidence of disablism. This is problematic because it leads to any social consequence of impairment being classified as disability. So, in the example of a family that misses out on going to the cinema, their exclusion is necessarily classified as an instance of disability. Dowling and Dolan stated: “Clearly, it is not the child’s impairment that is responsible for this type of missed experience, but other people’s behaviour and lack of support services” (p. 31). From this theoretical framework, it is hard to see how any activity restriction could be the result of impairment rather than disability. The

approach taken by Dowling and Dolan therefore risks overstating and oversimplifying the impact of disablism in creating material barriers in family life.

Goodley and Tregaskis (2006) took a different theoretical approach to that of Dowling and Dolan (2001), in that they considered the way in which the meaning of impairment and disability is socially constructed by both parents and services. These authors described what constitutes and supports enabling care for young children with impairment from the perspective of parents. They reported their analysis of interviews with five parents of young (aged 4 or 5) disabled children to obtain retrospective accounts of the care the children had received. They found that the parents worked out how to care for their child in a context in which services pathologised impairment and disability, and that the parents understood their child's impairment and the services they received in a way that resisted this pathologising. The parents actively used the uncertainty of their child's diagnosis to leave open many possibilities rather than limit the child's identity to "disabled", and to see their child's impairment as not the totality of the child. The parents understood their child and the services that they used in ways that promoted their identity as ordinary parents, and thus resisting seeing their lives as personal or family tragedy. They demonstrated a more nuanced understanding of their child's impairment and their child's needs than service providers. The authors concluded as follows: "Sadly, for many parents of disabled babies, the tendency of others to think they know better – and to subsume it under pseudoprofessionalized and institutionalized models of parenting – risks ignoring the parents' often more complex understandings of child care, parenting, disability, and impairment" (p. 643).

In this study, Goodley and Tregaskis (2006) focused on the relationship between parents of very young children and services, and the meanings of impairment and disability evident in their interactions. They did not claim to uncover the wider impact of disability on families, and they based their findings on the experiences of a small number of parents of very young children. One further small-scale study by Caldwell (2007) also used the social model with regard to families in the interpretation of its findings. This study examined the impact of changes and cuts to support services on families of adults with impairment. On the basis of interviews with nine families, Caldwell concluded that the perception by some parents of an imbalance of power between them and their service providers was consistent with a social model application to families.

It should be noted that the term “family” is a contested one; it has been argued by some feminists, for example, that the sexual division of labour in families, in which women have primary responsibility for caring work, perpetuates women’s dependence, and therefore that focusing on the needs and interests of “the family” ignores the needs of women within families (e.g. Dalley, 1988). Those studies that have used the social model to examine the situation of families tend to cast parents as protective and caring agents acting on behalf of their child with impairment. Other studies that take the perspective of the individual with impairment do not necessarily find that parents are always so benevolent. Thomas (1998), for example, concludes that parents can either champion their disabled child’s development and wellbeing or be a conduit of disabling ideas and practices.

## The current study

The social model offers a particular explanation of why disadvantage associated with impairment arises and is perpetuated. The reasoning is that the process of disablism causes disadvantaging barriers. An analysis from the social model perspective can identify the extent to which disablism, rather than impairment, causes family disadvantage. The studies by Dowling and Dolan (2001) and Goodley and Tregaskis (2006) offer some initial understanding derived from applying the social model to the situation of families with a child with impairment.

The aim of the current study builds on these foundations. Thomas' social model was chosen for my study for two particular reasons. First, Thomas' model affirms the social model perspective that restrictions on social activity for people with impairment are caused by disablism. According to Thomas, a barrier to social activity is a disability when it is wholly socially imposed. At the same time, Thomas' model allows that barriers in the lives of people with impairment can also be caused by impairment. Giving a place to the impact of impairment is critical because it is possible that the disadvantage that families with children with impairment experience might be due to their child's impairment rather than disablism. Thomas' model has the potential to identify the restrictions in everyday life that are disabling for families without assuming that any or all of those restrictions must be the result of disablism.

Second, Thomas' version of the social model considers both material and non-material dimensions. Thomas proposed that disablism is located in multiple levels (from the personal to the institutional and cultural) and dimensions (material and non-material) of social organisation. In doing so, Thomas extended the concept of physical

restrictions or barriers that disable individuals with impairment to include the impact of negative stereotypes, discourse, ideas and images on identity. Her non-material barriers to being have equal prominence with material barriers to doing. Her model is appropriate to the study of families with children with impairment because it opens up investigation of the potential of non-material factors, such as the impact of stereotyping on family identity.

Revealing how disabling barriers operate in family life has the potential to inform and change the way families with a child with impairment are understood, and consequently, consistent with the social model's concern for advocacy, to influence how families with a child with impairment can be supported in overcoming whatever disablism they encounter. If families are disabled along with their child with impairment, then understanding how disabling barriers operate in their lives, and in what circumstances families can overcome such barriers, will be important steps in identifying the kinds of social organisation that most effectively support families and their children to achieve their potential.

The overall aim of this thesis is to explore whether Thomas' concept of disablism applies to families with children with impairment, and if so, in what ways. There are two specific questions:

- (1) Does disablism in the form of barriers to doing exist for families with children with impairment, and if so, in what way?
- (2) Does disablism in the form of barriers to being exist for families with children with impairment, and if so, in what way?

## *Chapter 4*

### *Research Design*

#### Introduction

In Chapter 3 I described the disadvantage reported in the lives of families with children with impairment. To explore whether this disadvantage is evidence of disablism, I used Thomas' (1999) model to investigate everyday family life in a sample of purposively selected families. In this chapter I outline how I identified these families, information about the families, the rationale for the interview method I used, and how analysis of the data was conducted.

#### How the data were generated

##### *The larger research project*

This study was conducted within the context of a larger 3-year research project, the Maintaining Family-based Placements (MFP) project. The chief investigators of the MFP were Professors Gwynnyth Llewellyn and Anita Bundy. The MFP was funded by the Australian Research Council (ARC) within its Linkage Projects program.

Linkage Projects are research projects devised and conducted through collaboration between researchers and industry partners. The industry partner for the MFP was the Department of Ageing, Disability and Home Care (DADHC), which is the state

government department responsible for providing specialist disability services in New South Wales.

The aim of the MFP project was to develop and trial a clinical tool to examine the sustainability of family routines of families with children with impairment. This tool, called the Family Life Interview (FLI), was designed as a self report instrument completed by a parent following an in-depth semi-structured interview. The aim of the tool was to allow parents to describe their family's daily routine and the challenges they faced in creating and sustaining that routine, which would then assist clinicians to understand each family's daily life. By using the FLI, clinicians could more effectively plan intervention collaboratively with families to increase the sustainability of the family routine. In particular, the FLI aimed to assist in identifying families whose routines were not sustainable and who were therefore at risk of relinquishing their child with impairment to an out-of-home placement. The MFP project, including my participation as a PhD scholar, was approved by the University of Sydney's ethics committee (University of Sydney Human Research Ethics Committee approval number 02-2005/3/7930; see Appendix 1).

### *Theoretical foundation*

The theoretical foundation for the MFP study was ecocultural theory (Gallimore et al., 1989, 1993; Gallimore, Bernheimer, & Weisner, 1999; Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Weisner, Matheson, Coots, & Bernheimer, 2005).

Ecocultural theory posits that the core challenge for all families is to construct a sustainable and meaningful routine of family life. This is a family level project rather than an undertaking of individuals. Ecocultural theory provides an alternative to the family stress model of understanding family wellbeing for families with children with

impairment. Family wellbeing is understood as depending on the extent to which families are able to achieve a satisfying routine of daily life. Sustainability is theorised to depend on the extent to which the family's daily routine meets family goals and is consistent with family values, and on the extent to which family activities are able to balance the needs of all family members (Weisner et al., 2005).

Ecocultural theory takes a constructivist approach (Gallimore et al., 1989) in which the objective features of a family's social circumstances are thought insufficient to explain how and why families organise their everyday lives as they do. Rather, the pattern of families' daily lives depends on their understanding of both the challenges they face and the resources available to them to meet those challenges. The family's perspective on their needs and resources, their goals and values, underpins their daily activities. To access the family's point of view, the key method is to interview the primary caregiver.

The most important reason for using this method of family interview grounded in ecocultural theory in my study was that it accords strongly with Thomas' method for understanding the lives of individuals with impairment. Thomas developed her theory of disablism by analysing disabled women's accounts of their lives, arguing that "a detailed account of the day-to-day life of one individual ... tells us an enormous amount about disability and society in general" (Thomas, 1999, p. 78). In the same way, I also used detailed accounts of everyday family life provided through the MFP project to provide an entrée into understanding the impact of impairment and disability on the lives of families. Thomas argued that everyday life is the window through which to view the influence of the sociostructural on the lives of individuals

with impairment. In a similar fashion, ecocultural theory proposes that the everyday routine of family life reveals the social and cultural structures and processes within which individual families construct their routine (e.g. Gallimore et al., 1989). Thomas set out to understand the situation of individuals with impairment in their social context, whereas I set out to explore the situation of families with children with impairment. Ecocultural theory offered me a family level understanding of family daily life, to access the wider sociostructural influences upon the family.

A further consonance between ecocultural theory and Thomas' theory of disablism is that both give space to the impact of non-material factors as well as material factors. Thomas described non-material factors as just as important as material factors in erecting barriers in the lives of individuals with impairment. Ecocultural theory gives space to the impact of non-material factors on family wellbeing, in that the level of sustainability of family life depends on non-material family goals, values and beliefs, as well as on the material resources that a family can access.

Ecocultural theory acknowledges the importance of family agency in the construction of family routines. This is consistent with the concern of Thomas, and social model theorists more broadly, to recognise the agency of individuals with impairment. Some social modellers have expressed dissatisfaction with a theory of disability that explains the behaviour of individuals with impairment as a kind of reflex response to the disabling social structures in which they live, because this kind of explanation denies the capacity of individuals with impairment to exercise agency (Corker, 1999; Davis & Watson, 2002; Shakespeare, 2006). Thomas (1999) therefore described both the actions of women with impairment and the constraints of the disabling society

within which they take action. Ecocultural theory gives a role to family agency as families adapt proactively to their circumstances while at the same time acknowledging that families exist within a network of social influences (Gallimore et al., 1989).

#### *Development of the Family Life Instrument (FLI)*

The aim of the MFP project was to develop the FLI, a clinical tool to evaluate the sustainability of family life. The FLI was developed in a number of stages. First, a draft instrument was devised based on the ecocultural variables that had been found to predict 85% of family wellbeing in a previous study (Llewellyn et al., 2003). Sixteen questions were formulated by the research team to probe these ecocultural variables. Dimensions of family life that were explored through these questions were: “sharing workload and responsibility”, “balancing needs and demands”, “integrating the child”, “accessing special services”, “financial resources”, and “home and neighbourhood”. This draft interview was trialled with 38 families to test the narrative format of the interview, establish a logical question sequence and identify additional items of importance to interviewees in understanding their routine of family life. The interview guide that was used for these interviews is in Appendix 2.

Three members of the research team, of which I was one, conducted interviews for this first phase of the development of the FLI. Families were allocated to researchers so as to ensure that the workload for each researcher was evenly spread and travel time for interviews was shared evenly. First interviews were completed by the end of 2005. For this research, a family was defined as the household group in which the child with impairment lived. Consistent with ecocultural practice, the primary carer of the child with impairment was interviewed as the method by which to tap family daily

life. Gallimore et al. (1989, 1993) allow that different family members can have competing needs, but argue that the family project of creating a routine of everyday life includes balancing family needs, and is therefore an overarching family goal and legitimate object of study.

The next step in the development of the FLI was to revise the draft instrument by adding more questions based on the first round of interviews and a rating scale of family sustainability. This refined instrument was tested with the families who had participated in interviews in the first stage. The second interview with families took place approximately one year after the first interview. I participated in this stage of the project by interviewing the same 12 families that I had interviewed earlier. The interview guide used for this round of interviews is included in Appendix 2. The feedback from families was then used to create the next draft of the FLI. This refined version of the FLI was later trialled in the field by practitioners employed by the government disability agency, DADHC.

Conducting a second interview provided the opportunity for me to ask about any changes that had happened for families in the intervening year. For example, in the time between the first and second interview children moved from preschool and early intervention to the school system, and these changes impacted on their families. In particular, seeing changes for families over time gave me the opportunity to consider what influence, if any, disablism had on family experiences over time.

#### *Sampling method*

Participants in the first and second interviews for the development of the FLI were parents or primary carers of children with severe impairment identified by workers

from the NSW Department of Disability, Ageing and Home Care (DADHC). To qualify for DADHC services, a person must be either under 6 years of age with a developmental delay in at least two areas of functioning, or 6 years or above with an intellectual impairment (that is, a score two standard deviations below the mean on a recognised measure of intelligence) and “significant deficits in adaptive functioning in two or more areas” (DADHC, 2004).

Families recruited to the MFP study met the following criteria: their child represented one of three age cohorts (0-6 years, 10-14 years, 16-21 years); they spoke English at a level not requiring an interpreter, and they were eligible for services from DADHC. Families with children in three different age cohorts were invited to participate so that the FLI would be relevant to the concerns of families with children of various ages. DADHC workers were asked to recruit a range of family types, including “intact”, single parent and blended families, and families with and without other children, so as to ensure that the concerns of a range of family types were considered in the development of the FLI. Families from across three DADHC regions in the state of New South Wales were included, to ensure that families from urban, semi-rural and rural areas were represented. DADHC workers identified eligible families and gave them a project information sheet inviting them to participate. Those wishing to participate gave verbal consent to workers, who then passed on family contact information to the research team.

My participation in the MFP study was to conduct interviews with 12 families as part of the first stage of development of the FLI, and to subsequently reinterview these same families one year later. I used these interviews to address my research questions.

The sample of families on which my analysis is based is therefore small. The small number of participants in my study and the purposive way in which they were recruited means that I do not claim that the results of my study are representative of the experience of all families with children with impairment. However, building on the experiences of this small sample of families does allow me thoroughly and in depth to consider the impact of disablism, which is one indicator of quality in qualitative research (Silverman, 2005).

My study, and the MFP project of which it was a part, drew upon the ecocultural understanding that the family project of constructing and maintaining a meaningful routine of everyday life is organised by the parents in the family (Gallimore et al., 1989). The family project can therefore be accessed through the viewpoint of the parent who is most responsible for organising family daily life. In Australia, as noted earlier, the mother is usually the primary carer of the child with impairment. Therefore, in my study sample, it happens that for each family, it is the mother who represents the family and describes her family's daily life.

#### *Description of the twelve families in my sample*

This section provides a brief description of the 12 families who participated in my study. Each mother who spoke for her family is identified by a pseudonym. Some of the children had rare genetic conditions, so I have been somewhat general about the children's diagnoses and family issues, because there is a risk that families could be identified because of the rarity of diagnosis combined with particular circumstances. My family descriptions are derived from the field notes that I made as soon as possible after the first interview. I drew genograms of each family, showing the

family structure, the age of family members and their occupations, and noted what the mother said were the key issues for understanding her family's daily life.

Laura is in her 30s and does flexible shiftwork in the disability industry. She has three children, and lives with her partner and his three children. Her middle child, Tianne, who is 12, has an intellectual impairment and epilepsy. Tianne does not cope well in large social groups, does not sleep well, and her behaviour has "autistic features". Laura feels that the family cope well with the challenges that living with Tianne can bring. Between the first and the second interviews, Tianne moved from primary school to high school. The family have experienced considerable loss and trauma, and there are also "blended family issues", so the challenges of Tianne's impairment are not the only issues that the family deals with. Indeed, at the time of the second interview, Laura had separated from her partner. The family are not wealthy, and rent rather than own a home, but Laura feels they have enough to get by and do not go without. She does not think that the family has suffered financially from her separation from her partner. The family live in a small country town, which Laura thinks is a healthy alternative to the more difficult and deprived urban environment in which they lived previously.

Maureen is a single parent in her 20s with one child, Danny, who is 4. Danny has an intellectual impairment as a result of a rare genetic condition. Maureen has chosen not to work while Danny is under school age, and she receives government income support. She lives in government housing, and does not like the neighbourhood in which she lives. Maureen experienced abuse in her childhood. She has a good relationship with Danny's father, and supportive and regular contact with some of her

family. At the time of the second interview, Maureen was looking forward to Danny starting school, and had a clear plan of which school he would attend.

Yuki is in her 30s, and lives with her husband and their only child, 4 year old Luca. Yuki is from a non-English speaking background. Luca has an intellectual impairment and epilepsy as a result of a rare genetic condition. He receives a number of early intervention services. Yuki is uncertain as to what services will continue for him when he starts school, but services until now have been fairly easy to access. Yuki works part-time, and feels that her career has been restricted, but feels that this is due to the heavy demands of her husband's job rather than the caring needs of Luca. At the time of the first interview, the parents were debating whether to have another child, a debate that did not appear to be resolved by the time of the second interview.

Diane is in her 40s, and lives with her husband and only child, William, on a rural property. William is 19 and has a severe intellectual and physical impairment. Diane cares for William full-time, and William attends a part-time social program run by the local disability service. The family are not wealthy; they "get by" on a rural labourer's wage and do not own their home. By the time of the second interview, Diane's husband had changed jobs to work in the disability industry, which is better paid than his previous job, and the family were enjoying a better income. Diane is a passionate advocate for her son and her family, and is satisfied that William's development continues to progress.

Belinda is in her late 30s and lives with her husband Jim and four children in a small town on the fringe of Sydney. Her youngest child, Leo, is 4, and has severe

intellectual impairment, physical delay and a hearing impairment. Between the two interviews, Leo moved from early intervention services to school, and Belinda compared the issues that he and his family face with each of these service systems. Belinda is also starting to use a home-based respite service. The family are not wealthy; they manage on Jim's labourer's wage, but have been able to buy their own home. Leo needs specialist equipment which they struggle to afford. Despite these struggles, Belinda feels that the family cope well with Leo's impairment since his medical problems have settled.

Janice is in her 40s and is the mother of four children. She lives with her husband and children in suburban Sydney. They own their home, and this requires both Janice and her husband to work full-time. Her oldest child, Stephen, is 22, and has severe physical and intellectual impairment. The family has home help in the morning to get Stephen out of bed and ready for the day program that he attends part-time. Janice thinks that the family cope well with caring for Stephen, although they were stressed when Janice was hospitalised with mental health problems about a year before the first interview. At the time of the second interview Janice was planning to move to a larger home to accommodate her family.

Jean is in her late 40s and has one child, Kevin, who is 16. Although Jean's husband works full-time in a professional job, Jean feels that the family struggle financially. They own their home, but it is in poor repair, in part because Kevin, who has autism and challenging behaviours, has damaged the doors, windows, floor and bathroom. At the time of the second interview, Jean was looking for a post-school program for him.

Mary, who is in her 30s, has four children, three of whom, aged 8, 11 and 16, have mild intellectual impairment. Mary's husband works as a labourer, and they own their own home in a neighbourhood that they like. Both Mary and her husband are from a non-English speaking background. At the time of the first interview, Mary was most concerned that she was unable to obtain a special class placement for her youngest child, and during the second interview Mary said that she was most worried about her children's future work prospects.

Shauna is in her 30s, and has two children. Her younger child, Jenny, is 5, and has a rare genetic condition that results in a severe physical impairment and a communication impairment. Jenny's life expectancy is shortened because of her condition. At the time of the first interview, Shauna's husband was working on a short-term contract interstate, and Shauna had been unable to do paid work because of caring for Jenny. By the time of the second interview, Shauna's husband had found work back in Sydney, and Shauna herself had started work as a teacher's aide, which she finds very satisfying. The family live in a rented home in an area that they like, but they cannot afford to buy a home.

Sam is in her mid-40s, and is married with three children. Her middle child, Peter, is 16, and has autism and challenging behaviours. The family are well-to-do, and live in one of Sydney's wealthier suburbs. Living with Peter has been challenging, but he is now fairly settled on a regime of medication that Sam monitors closely and adjusts regularly. Peter attends a special school, and Sam is uncertain about what the future holds for him. Sam herself would like to do professional work, but has been unable to

fit this in with the rest of the family's timetable. At the second interview, Sam's concerns about the future for Peter and her family continued.

Trudy is in her 40s and is a single parent with one child, 12-year-old Matthew. Trudy receives government income support, and the family live in government housing. Matthew was born very premature, and has severe intellectual and physical impairment. Matthew has no contact with his father, but Trudy has a partner who spends time with the family and who helps care for Matthew. Trudy is unable to do paid work because of caring for Matthew. Trudy thinks that her family life is going well now, but wonders how she will cope in the future as Matthew gets bigger as she is finding the physical care work increasingly hard. Her uncertainty about the future for Matthew continued at the time of the second interview.

Nisha is in her early 40s, and is married with three children. She has two teenage children and one preschooler, 4 year old Dean who is developmentally delayed. Both Nisha and her husband are from a non-English speaking background. Nisha's husband works full-time in a professional job and the family own their home in an area that they like. Nisha used to do office work, but stopped when Dean was born, and, once his delay became apparent, she did not return to paid work. Dean has epilepsy and severe intellectual impairment; at the first interview, the reason for his delay was unknown, but by the time of the second interview, Nisha had found out that he has a rare genetic condition. Nisha is glad to have found out that there is a reason for Dean's impairment, but wonders whether this will affect her older children finding partners. Between the first and second interviews, Nisha also had to decide on where Dean would go to school.

As these brief sketches indicate, the children in my sample of 12 families reflect a broad range of impairments. Children such as Jenny, Matthew, Stephen and William have severe physical impairment; other children such as Dean, Peter and Kevin are physically active and independently mobile. The behaviour of some of the children is challenging: Kevin and Peter are autistic, and Kevin damages his home and Peter has been violent to family and workers, while Tianne's behaviour has "autistic features" and she does not cope well in some places. Three mothers in my group of twelve families, Mary, Nisha and Yuki, are from non-English speaking backgrounds. Family income and socioeconomic background vary; some families have sufficient income whereas other primary carers, such as Maureen and Trudy who are single mothers on government benefits, struggle financially.

#### *The interview process*

For the purposes of the interview I sought the view of only one parent, the person who was most responsible for organising the family routine. In all cases, this was the mother, who identified herself as the primary carer. However, during two family interviews the father, who was not present initially, arrived home during the course of the interview, and then joined in. Whether children were present at the interview depended on the mothers' preferences. All the interviews were conducted in the family home. Funding in the MFP project allowed for child care if the mother requested, but all the mothers I interviewed preferred to work around their usual commitments and resources rather than call in a carer especially for the interview. Each mother decided whether it was suitable for the child with impairment or other children to be in the home or in the room where the interview was conducted.

Interviews were conversational in nature, in line with the ecocultural method. Each interview began with asking the mother to describe the family routine of daily life. Probe questions were used as needed if aspects of family life in the interview guide were not spontaneously included in the mothers' narrative descriptions. Interviews lasted between one and two hours. I taped the interviews, and afterwards transcribed them, the majority with assistance to complete all transcriptions.

### *Field notes*

I documented the interview by tape and transcript, and also made field notes of each of my meetings with families. The field notes recorded my impressions of what I saw and heard (Emerson, Fretz, & Shaw, 1995; Silverman, 2005). I described the family home, how physical space in the home was organised, the interactions I observed between family members, and the interaction between me and family members. Keeping field notes served a number of functions. The notes gave me a summary of the content of the interview. This provided a data base about the families, to which I could refer for explanatory purposes, such as at research team meetings. A second function was to record the communication that happened before and after the tape was turned on. A further function of keeping field notes was to record my thoughts and impressions at the time of the interview. This record was then a source of information that contributed to my analysis of the interviews.

One example of how field notes contributed to my research process comes from my meeting with Maureen and her son Danny. I noted in my first meeting with Maureen that after the tape was turned off at the end of the interview, she showed me some photos that she had taken of Danny not long after he was born. The photos showed a sick little baby in hospital. Maureen then explained that Danny was very ill as an

infant and spent many months of his early life in hospital. Seeing these photos helped me to understand that this now robust little boy had been so vulnerable as a baby and that his very survival had been by no means certain. This helped me to understand better Maureen's words about doctors warning her not to expect much of him, and how delighted she was that she and Danny had proved them wrong.

At the time of the second interview I noted in my field notes that there were decorations in the room that had been left up from Danny's recent fifth birthday party. For Maureen, Danny's fifth birthday was an important milestone, because it was his last birthday before starting school, and she had made a decision to devote herself to caring for Danny full-time and not to do paid work until Danny reached school age. The field note descriptions helped in my later analysis when I reflected on how Maureen described Danny, how others saw him and what he had achieved. Maureen felt satisfied about his (and therefore her) achievements despite the negative expectations or ideas that others held about him. My field notes reminded me of the "feel" of the interview and added to my understanding of Maureen's descriptions in the interview of what she did in response to negative ideas about her child.

#### *Supervision meeting notes*

In addition to interview transcripts and field notes, I kept a written record of supervision meetings taken from a tape recording. My supervision meeting notes documented the issues in analysis that were discussed in supervision, how these might be tackled and the time frame in which this work was to be done. Keeping notes on analysis was recommended by Spradley (1979) as a way to develop and deepen the research process. My supervision notes documented the steps I took in analysing data and answering my research questions. As such they form part of the audit trail that

contributes to the validity of the interpretation that I offer in the findings chapters (Silverman, 2005).

An example of how my supervision notes contributed to the process of analysis comes from my meeting notes from 12.03.07. Before this meeting I had prepared some written material on the theme of valuing by parents of their child, themselves and their family as a whole. I had developed these ideas inductively from the material in the first interviews, but had not yet linked this understanding of how families understand their child and themselves to the potential impact of the non-material dimension of disablism on families. I had some descriptions of what families did and how they saw themselves, and my supervision notes say: “A lot of the stuff [...] is not about are families disabled, it’s just about how they organise their lives. What evidence is there that these families are disabled?” This was an important signal that it was time to directly answer my research questions. How I went about this is described in the next section.

## Conducting an analysis

### *A two-step process*

Disablism is a theoretical concept. It is an “experience-distant” concept, quite distinct from the “experience-near” practical concerns (Geertz, 1983) that families with children with impairment manage in their daily lives. In investigating Thomas’ theory of disablism and its applicability to family life for families with children with impairment, the challenge I faced was not to assume that family life would necessarily be influenced by disablism. I wanted to remain open to understanding family life as

having multiple influences, one of which could be disablism. I was concerned that if I simply examined the family life of families with children with impairment, looking for evidence of barriers in their lives, and then pointed to these barriers as evidence of disablism, I could be doing little more than confirming a pre-held view. One of the ongoing challenges of this study has been to balance my focus on the theory of disablism with my focus on the lives of families with children with impairment.

To avoid a pre-emptive decision on disablism affecting family life, I undertook analysis in two steps. I developed a description of the daily lives of families via the data collected for the MFP project, rather than asking families to focus directly on whatever barriers they felt that they had experienced as a result of having a child with impairment. In the first step in analysis, I used inductive methods to become familiar with and explore the stories that mothers told of their daily lives, and to develop an understanding of their families that was grounded in the “experience-near” accounts of their daily lives. At the start of analysis, I understood disablism to be a “sensitising” category (Glaser & Strauss, 1967) among many others with which I was familiar from the literature, such as the effects of impairment, stress, and disadvantage (as described in Chapter 3).

### *The inductive stage*

Analysing my data involved listening to and reading transcripts of the interviews I had conducted, pondering, asking questions about the interviews, comparing the interviews, rereading the transcripts, and pondering again. Plummer (2001) notes that this process is difficult to describe and capture. In order to first build up a picture of family life inductively, I started by using some of the methods of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998). One of the foundations of

grounded theory is the use of open coding to break the data into conceptual parts, and to interrogate those parts and their interrelationships. This part of grounded theory appealed to me as a novice researcher because there are specific and practical suggestions for how to conduct the initial coding process (Browne & Sullivan, 1999; Richards, 2005; Strauss & Corbin, 1998).

The process of open coding involves developing the ability to question data, and to push analysis to a more abstract level beyond the immediate concerns of research participants. Dey (1999) suggests that open coding is not a clerical or routine procedure; it is an analytical procedure that stimulates further questioning and analysis. Although not specifically using grounded theory as a framework, I followed Richards' (2005) advice that all researchers can benefit from the skills of open coding.

I carried out open coding of the transcripts of both rounds of family interviews. This involved breaking each interview transcript into segments and allocating these segments to codes, following the guidelines of Strauss and Corbin (1998) and Richards (2005). In order to “get up off the page”, as Richards put it, I asked of each transcript what the family was doing, what I found interesting and why I found it interesting. Examples of codes at this stage include “impairment work”, which named the work that family members did that was to do with, for example, transporting or feeding their child with impairment; “describing family relationships”; and “identifying problems”, which grouped together the things that mothers saw as problems or difficulties in their families that were not necessarily specific to impairment or disability. I used the software package NVivo7 (2006) because this program made it easy to put interview segments into more than one code and also to

go back to the place in the transcript where the segment was situated. When using NVivo, a definition of each code can be attached to help ensure that the code is used consistently over time and data sources.

I was challenged by my supervisors to name codes using an active voice, and to focus on what people were doing, not just coding by the things they were describing. As Charmaz (2000) suggests, action codes are more useful: “Generating action codes facilitates making comparisons” (Charmaz, 2000, p. 515). Coding the first round of interviews resulted in generating 58 codes to do with family life. As an example of the coding process, I coded a mother describing her difficulty in accessing a transport scheme for her daughter who uses a wheelchair. I coded this item in four places: “describing transport”, “relationship with services”, “identifying problems” and “parent advocating”.

During this first inductive stage, I also took a course in qualitative methods for which the text was by Silverman (2005). Silverman is a conversation analyst, whose approach to analysing the meaning of interviews emphasises the social nature of interviews in which the interviewee displays her or his identity to the interviewer. Silverman suggests that this subtext underpins and works with the content of what the interviewee says, and that this understanding of the research interview can yield valuable insights.

This course sensitised me to the rhetorical aspects of mothers’ narratives in the interviews. That is, I became increasingly aware not just of the “what” or descriptions of family life, but also of how the mother presented herself and her family in the

interview. I came to better understand Holstein and Gubrium's (1995) perspective on research interviews. Holstein and Gubrium conceptualised the research interview as a process created together by the researcher and interviewee, rather than a process in which the interviewee provides information to the interviewer in a process akin to water being tipped from one vessel to another. For Holstein and Gubrium, the content of what the interviewer says is only one part of the interview, and the process and content of the interview work together to create shared meaning.

How mothers described their concern about balancing the needs of their child with impairment with the needs of their other children illustrates this point. Not surprisingly, families differed in how they balanced the needs of their child with impairment with the needs of their other children. For example, Janice and Sam kept their other children away from any responsibility for the caring tasks for their brother, whereas Belinda and Laura actively involved their other children in caring for their brother or sister. Ecocultural theory explains family activity as accommodation (Gallimore et al., 1989); accommodations are different across families but all have the common goal of balancing the needs of all family members to create a meaningful and sustainable routine. But along with the "what" of the accommodations of family life, and the "why" of creating a meaningful and sustainable family life, mothers described the level of responsibility they undertook as a parent and mother in managing the involvement of siblings in caring tasks for the child with impairment. In explaining to me what they did to balance the needs of all their children, these mothers were demonstrating their identity as good mothers who weighed the needs of their children in organising their daily family life.

I developed inductively derived codes from the two sets of family interviews to describe family daily life, conducting separate coding on each round of interviews. I reviewed the coding of the first interviews before coding the second interviews so as to be sensitised to any new information, such as changes in family life, in the second interviews. Conducting open coding and undertaking a course developed my understanding that when mothers described their family life in interviews they were also displaying their identity as good parents and families. Parents were describing their actions as parents organising their family lives, and they were at the same time showing me the value of their child and family. I wrote theoretical memos (Richards, 2005) about this emerging understanding of the interviews. I was then ready, as I reported earlier in describing my supervision notes, to take the next more deductive step.

#### *The deductive stage*

The next step was to address my research questions directly and relate the understanding of family life I had developed through sustained examination of families' descriptions of their everyday life to the concept of disablism. This second step of analysis was a deductive one in which I took Thomas' definition of disablism and reviewed the codes of family life that I had developed from the first and second interviews, to examine whether Thomas' concept of disablism applied to family life for families with children with impairment. I reviewed all the interview codes for evidence of barriers in family life, and asked myself whether each barrier was evidence of disablism.

Deciding whether restrictions in family life are evidence of disablism is by no means straightforward, because, as Thomas admits, the concept of disablism is subtle and

difficult to pin down. Furthermore, disability and impairment effect occur together, and impairment is bio-social, so it is not straightforward to distinguish disadvantage that is the result of impairment from disadvantage that is disablism. In order to identify disablism, I studied Thomas' definition of disablism as an unequal and oppressive relationship, and examined the codes created from mothers' descriptions for signs of this relationship. I had to consider what would indicate disablism because, as Thomas has said, the concept is subtle and much is implied by it. One of the reasons that disablism is not always clear-cut is that family members might feel imposed upon by social processes other than disablism, such as the lack of choice imposed on families through poverty (and to complicate things further, poverty itself is linked to impairment). Families might also experience barriers and so feel that they lack choice because of impairment effect, rather than disablism. Thomas has argued that impairment effect and disability are intertwined in the daily lives of people with impairment and cannot therefore be neatly separated. I worked from the assumption that this might also hold true for families.

My rule of thumb for deciding when restrictions in family life were evidence of disablism rather than impairment effect or another oppressive force was to compare the situation of my study families with hypothetical families in similar circumstances but with typically developing children, asking whether a restriction in opportunity for my study family was linked to impairment, and asking whether there were features of oppression in the family's experience of the restriction. For example, when I considered single mother Trudy's inability to work, I considered that a single mother in a similar position but whose child did not have an impairment would most probably be able to work if she so wished, because before and after school care are widely

available for non-disabled children. Therefore Trudy's inability to work was likely to be due to having a child with impairment rather than to being a single mother. Trudy wanted to work but was unable to do so. Her lack of choice was due to lack of child care options rather than a "natural" consequence of her child's impairment, and therefore I considered it to be an instance of disablism

I found this task of identifying disablism demanding, because it involved a constant tacking backwards and forwards between the theory of disablism and the actuality of family life with a child with impairment. To manage the task, I separated the two dimensions of disablism that Thomas described, and first examined family life for evidence of restrictions in material life. I then organised the disabling material restrictions that I found using the method of constant comparison (Glaser & Strauss, 1967), which meant comparing barriers and grouping together those that were similar. I arrived at a tentative grouping of four kinds of barriers to doing that showed features of disablism, which I report in Chapter 5.

Thomas also defined disablism as manifested in barriers to being, which affect psycho-emotional wellbeing. I reviewed Thomas' definition of barriers to being and then reviewed my codes to see whether they contained evidence of this type of barrier. This involved doing more than looking for evidence of emotional distress in family members; Thomas stated clearly that barriers to being are only evidence of disablism when emotional distress is caused by prejudicial attitudes and ideas about impairment. I therefore looked for evidence of the impact of prejudice on family members and described the impact of such encounters.

I found, however, that I could not organise this material on the impact of prejudice in the same way as for barriers to doing. For barriers to doing, I could group instances according to the content of the barrier, whereas for barriers to being, I could organise material by family actions, rather than what they were reacting to. In Chapter 6 I outline how families perceived and responded to prejudice about impairment.

## Conclusion

In this chapter I have presented the methods I used in my study, and the reasons why. I have also described the analysis process. I present the results of this study in the next two chapters, starting with the material dimension of disablism in family life in Chapter 5, and then considering the impact of the non-material dimension of disablism on families in Chapter 6.

## *Chapter 5*

### *Material restrictions and disablism*

#### Introduction

Families in this study reported disabling material restrictions in their daily lives related to having a child with impairment in mothers' participation in paid work, family finances, leisure, and in their relationships with services. This chapter presents these restrictions and family responses. I conclude with theoretical statements of the circumstances in which material restrictions can be regarded as instances of disablism.

#### Family organisation of paid work

This section reports the restrictions on how families managed organising their paid work, especially the participation of mothers in the paid workforce. The mothers varied in the extent to which they experienced their decision to work or not to work as a choice. Maureen said she made a choice not to work because of her child's impairment. She felt that her son Danny did not cope well with child care and was better off staying home with her full-time, and doing early intervention with her, until he started school. For other mothers, the decision not to do paid work was not attributed to their having a child with impairment. Belinda and Mary, for example, did not do paid work because they had large families, and wanted to be at home to care for their children.

For other mothers, deciding not to work was not experienced as a choice. For these mothers, their caring responsibilities precluded them from choosing whether or not to work. For example, Trudy, a single mother, did not do paid work, because she needed to be available outside school hours for her 12-year-old son Matthew, who has severe intellectual and physical impairment. She has a back problem caused by lifting him, and this also limits her paid work options. She would like to do paid work in the field in which she had experience and qualifications, but it was just not possible because the flexibility and shorter working hours she needed were not usually on offer. To her, “it’s ridiculous” that she could not do paid work; but she said that she must accept her circumstances and so does not complain about her caring responsibilities restricting her ability to do paid work.

Samantha’s circumstances were quite different from Trudy’s, but she too was resigned to being unable to do paid work. Samantha was regretful about this. She has a professional qualification and undertook a refresher course with the idea of re-entering the workforce. However, she found it impossible to accommodate her wish to return to paid work within the family routine, because she had to be at home when her son who has autism returned from school. She felt her family was not really financially disadvantaged by her not doing paid work, but was disadvantaged in that the family has a mother who feels thwarted because she is prevented from exercising her professional capabilities.

When the primary carer is restricted to doing little or no paid work in two-parent families, this may also constrain the paid work of the main breadwinner. Nisha, for

example, stayed home to care for her preschool child who has severe intellectual impairment, while her husband felt that he had no choice but to work at a job he hates in order to provide for his family. This situation may not appear to be much different to the situation of any other family with dependent children. However, the restrictions and compromises in paid work organisation may continue for much longer for families with a child with impairment. So, for example, Nisha has had to take her son to numerous medical and early intervention appointments from infancy up until school age, which made it impossible for her to return to her job when her maternity leave expired as she had done with her other children. The restriction on Nisha's paid work in turn affected her husband's work; if Nisha cannot work, then he cannot afford to take risks with his work security. Samantha, with three teenage children, was unable to get back into the paid workforce even though she wanted to, at a time when mothers are usually freed from hands-on caring for their children and thus more available to do paid work.

For Shauna, the negative impact of not being able to do paid work on her family was above all financial:

But it's hard just, not being able to work full time. If Jenny was a normal child, I'd be able to go out and work full time during school hours and we'd have money to take proper holidays and to do things that other families do. I mean we rent this place, we haven't got a hope of buying a house, with one of us working, it's just not going to happen. It would be nice. I do feel like I'm kind of stuck in limbo, you know, like I can't bring – I have a good life, with, you know, lovely children and a nice husband, but you can't move forward like other people can because there are restrictions there.

Another parent, Diane, was unable to combine paid work with caring for her young adult son, and she protested about her inability to earn an income. She objects when other people, including members of her extended family, tell her that she is simply

meeting her responsibilities towards her child, and therefore should not expect to be included in the paid workforce. She is outraged because she sees that she works very hard, harder in fact than those in the paid workforce, and her work never stops, but her work is unpaid.

Mothers in this study also talked about the satisfactions and rewards of their unpaid work. Trudy, a single mother who was unable to do paid work, said she was lucky that she is able to care for her son and that this was her full time job, even though it was unpaid. She thus linked the value of her unpaid work to the world of paid work. Mothers in this study demonstrated the value of their unpaid work by showing how it equipped them better to do paid work. As a result of their intimate knowledge of impairment via their unpaid caring work, some parents had found paid work in the disability area. Diane, the mother of a young adult with severe intellectual and physical impairment, talked about the gain for her husband George in starting work in the disability area. She described George as feeling successful and valued in his new job, in contrast with some of his other life experiences. The value of his paid disability work is, for Diane, directly tied to the quality of the unpaid caring work that he does with his son. Although unhappy that she is unable to do paid work herself because of caring for her son, she was clear about the value of her caring work, because if she too could market her skills, she would earn well: "But I've learned so much. Could be earning big dollars."

When the mothers in this group did do paid work, they had to organise care for their child with impairment. For example, Laura needed to work to support her large family financially, and she was able to work casual shifts because her eldest daughter could

supervise her child with impairment before or after school. Yuki was able to work part-time while her young son was at preschool. Yuki felt frustrated that she could not pursue a career, but felt that this was more to do with the compromises that she had to make because of the demands of her partner's job rather than because of the particular caring needs of her son. Janice was one of two mothers who was able to organise care for her child so that she could work close to full-time hours. The other was Shauna who by the time of the second interview had found a job in school hours. Her new job gave Shauna much satisfaction, and she was on the path to reducing the financial barriers in her family's life.

For financial reasons Janice has to work, since she has a mortgage and a large family. Her oldest child Stephen is a young adult with severe intellectual and physical impairment. She has a service that comes to her home to care for Stephen in the mornings, so that she can leave early for her work, but she says that organising this service is a "pain in the arse". She has to take whatever carer is allocated to her son by the home help agency, so she feels she has little choice about the carer Stephen gets, and is not happy that he ends up with the agency's least competent carer. She tries to tell the carer how to be more sensitive to her son, but does not think the carer listens. She just has to take the carer the agency sends, even though she thinks he is unsatisfactory. Thus although Janice is able to do considerable paid work, her experience nevertheless has something in common with those mothers who would like to do paid work but cannot, in that she has little choice or control about her son's care that enables her to work.

Shauna, Trudy, Samantha, Diane and Nisha would have liked to do paid work, so their non-participation was not simply a result of a personal preference to be an at-home mother. Their experience is consistent with those studies which have found that mothers of children with impairment are less likely to do paid work (AIHW, 2004; Parish et al., 2004), that severity of impairment is associated with less likelihood of mothers working (Gordon et al., 2007), and that constraints on paid work are of concern to mothers (Gordon et al., 2007; Read, 1991). The barriers to paid work reported by the mothers in this study are consistent with the barriers reported in other studies, such as lack of alternative appropriate care and the care needs of their child (Dowling & Dolan, 2001; Gallimore et al., 1993; Gordon et al., 2007; Olsson & Hwang, 2003; Parish, 2006; Todd & Jones, 2005). The negative consequences of being unable to work for mothers in this study are similar to those described for other groups of mothers in terms of role restriction and financial disadvantage (Eisenhower & Blacher, 2006), and feelings of isolation, frustration, and lack of fulfilment (Shearn & Todd, 2000).

#### *Disablism and family organisation of paid work*

Constraint in participation in the paid workforce is a restriction in social activity that has long been identified as a disabling barrier for adult individuals with impairment (Barnes, 1997; Oliver, 1998). But is the reduced participation in the paid workforce for mothers of children with impairment, and the negative consequences for mothers and therefore their families, also attributable to disablism? Thomas described restriction in social activity as a barrier to doing, but she allowed that restrictions or barriers can be the product of impairment as well as disablism. Restriction in workforce participation for mothers of children with impairment could be considered to be an impairment effect if it is a necessary entailment of impairment. So, for

example, when Shauna objects to her exclusion from paid work and its consequences for her family, it could perhaps be argued that her exclusion is an instance of impairment effect rather than disability. When restriction on maternal paid work is understood in this way, caring for the child with impairment is seen as the foremost maternal responsibility, before employment. If the restriction is an impairment effect, there is also an assumption that the family's responsibility is to provide whatever care the child needs. The argument would be that restriction from the paid workforce compared to other parents comes from responsibility to care, a private concern of the family, and the family is fulfilling its duty by taking care of their child.

Parents do have a responsibility to care for their children, to the extent that the state intervenes where children are deemed to be not adequately cared for. However, responsibility for ensuring the wellbeing of children does not rest solely with parents, or even mothers. The problem with understanding constraint on workforce participation as impairment effect is that it relegates all responsibility for the care of the child with impairment to the family, when wider social institutions too share the responsibility of bringing up children, as evidenced in state-mandated and funded education and health programs and tax policies that favour families over the childless. Bringing up children, therefore, is not solely the private concern and responsibility of families. Where the negative consequences of bringing up children with impairment are greater for families with children with impairment than for other families, this differential disadvantage is not solely the private concern and responsibility of families.

Thomas (1999) argued that, for adult women, even when the disadvantage of impairment is experienced as private, it is not necessarily an impairment effect, and may in fact be disabling if it arises from an unequal and oppressive relationship. This argument may also apply to families with children with impairment. The disadvantage for these families in restriction on mothers working, although experienced as a family matter, is not necessarily an impairment effect. There are aspects of the restriction in undertaking paid work that mothers such as Shauna experience that suggest disability rather than impairment. If Jenny was a typically developing child, Shauna would have access to child care options that would enable her to work. Child care is an organised pattern of social behaviour, involving child care services with skilled staff, or family day care by mothers, which is not available to Jenny. When child care services are unable or unwilling to accept Jenny, then Shauna's inability to access child care is not a natural consequence of Jenny's impairment; it is socially constructed. Lack of choice for mothers with regard to paid employment is not an automatic product of their child's impairment. All children have care needs. Jenny has little or no choice in terms of before- or after-school care, and consequently Shauna has little or no choice in paid work. This lack of choice compared with other mothers would seem to be evidence of disablism.

So far, I have suggested that the restriction on workforce participation for mothers of children with impairment is akin to the disabling barriers experienced by individuals with impairment. But even when mothers are able to access appropriate care for their child so that they are able to undertake paid work, another form of disablism may operate, through the way in which the care is provided. For example, Janice's experience regarding services is that she has to accept on behalf of her son a carer

who handles her son roughly and is insensitive to her feedback. She feels that she has little choice but to accept this carer and that the service in general is unresponsive to her concerns about the quality of care provided by this carer. This suggests that there is an unequal power relationship between Janice and the service. (The potential for services to operate in disabling ways is explored further in a later section of this chapter.) Janice's experience may be similar to the experiences of individuals with impairment, but, perversely, Janice experiences this kind of disablism in order to get to work and avoid another kind of disablism, which would for her and her family be the considerable disadvantage of her not doing paid work.

When mothers of children with impairment want to do paid work but are unable to because of the care needs of their child, their decision to not work is imposed rather than freely chosen, in that the child care options available to other mothers are less available or unavailable to them. The restricted work opportunities that mothers of children with impairment experience compared with their peers who have typically developing children are the result of the way in which social patterns of care are organised, excluding them.

*When mothers of children with impairment are unable to perform paid work, and when this restriction is not an impairment effect, this is disablism.*

## Financial costs

Families in this study faced extra expense because of their child's impairment. The extra expenses ranged from buying special equipment, such as vans or wheelchairs, to nappies, to special foods and medicines, and the costs of therapies and medical visits.

Travel expenses were a particular concern for families who lived in the country and needed to travel to the city for services.

The ways in which families experienced and responded to the financial costs of impairment, and how the financial costs of impairment interacted with the financial state of the family in general, are presented here by describing families from the study with low, middle and high incomes. Trudy has a low income. She is a single parent who is unable to work and who receives a government parenting allowance. She is able to manage financially because she lives in government housing, so her rent is below market level, and because she can ask for help with bills from her mother when her debts accumulate. Despite this, there are times when she has to choose between paying a bill or buying food, and she feels stressed about not having enough money. She faces one particular expense in the future that she cannot afford, even with help from her mother. Her son has a severe physical impairment, and she has a van which accommodates him in his wheelchair, but this van is reaching the end of its life. Trudy does not know how she can replace the van because, even secondhand, these vans are very expensive and out of reach for a pensioner. She plans to ask charities for help. The process of applying to charities will be time-consuming and the outcome uncertain.

Shauna's family income is greater than Trudy's because Shauna has a partner who works full-time, but, like Trudy, Shauna faces the problem of how to pay for expensive equipment. The family have enough income to pay for rent, food and bills, but not to buy the expensive equipment that Shauna's daughter Jenny needs. At the time of the first interview, Shauna was unable to do paid work. She raised funds to

buy an electric wheelchair by making “endless chocolates” to sell. She saw the wheelchair as a priority for her daughter because “other kids were getting around, I wasn’t prepared to wait”. Shauna’s family have also helped with the cost of other pieces of equipment. Shauna wanted to access the system that subsidises wheelchair taxi costs, because the family did not have a vehicle that could accommodate Jenny’s wheelchair. Their application was refused because Jenny was under 5 years old. This, Shauna says, is a good example of the constant frustrations and battles she faces in accessing the help she needs.

Samantha’s family have a high income. Samantha would like to work, but is unable to because she cannot fit it into the family’s timetable. The income forgone in her not working is not a major cost for her family, because of her partner’s high income.

Samantha identifies the financial costs of impairment as an essential part of the difference and, for her, disadvantage, of having a child with impairment:

I just think everything is an obstacle. Everything’s an issue that’s cutting into your freedom, cutting into your jobs, cutting into your finances, cutting into the way you relate with your family, your friends. Everything. Everything is different. And I think it’s not until you have, they get a bit older and perhaps, and maybe because life for us got better, you can have a bit of objectivity

Despite her family’s relative affluence, for her teenage son Peter to have the adult life she would like for him, and in particular for him to have supported accommodation away from his parents, it would take more money than they have. She would like not to live with Peter forever, but sees little alternative for him or her, because of the limited alternative home options for him. Samantha says ironically:

It would be interesting to see if there were better ways to look after him with the help of someone else’s money.

Samantha also points out that the pension her son receives does not even cover the cost of his medications, let alone any other of his living expenses. For Samantha's family, the financial costs of caring for Peter are considerable and ongoing.

There was a tension in how the mothers viewed the additional expenses they faced. This tension arose from their willingness to meet these additional expenses, but at the same time a wish not to be unfairly financially disadvantaged by the costs of impairment. Janice's description of how her family manage the costs of impairment illustrates this tension. Janice's family have many expenses related to her oldest son Stephen's impairment, such as needing a van, an electric wheelchair, nappies and formula. Stephen is getting taller, so they need another van that is big enough to accommodate him in his wheelchair. Janice is clear that she and her husband are responsible for taking care of all their children, and this includes financial responsibility for Stephen and the extra costs they face because of his impairment. Friends had earlier banded together and organised a fundraising night which raised \$19 000 for equipment for Stephen. For Janice, accepting the money "nearly killed" her, because she was reluctant to accept charity, and she says that she would not do it again. Janice is proudly independent and does not want to ask for a handout, but at the same time, she does not really think that having all these extra expenses is reasonable. They have extra garbage to dispose of such as nappies and empty formula containers, and they have to pay extra to their local council to have a bigger garbage bin. This, she says, is not fair because they have no choice but to produce this extra garbage. She feels that the family are penalised for something over which they have no control.

The restriction on mothers participating in the paid workforce, which was discussed in the previous section, matters to families in part because the family forgo the income that the mother could have otherwise earned, and may be at greater risk of financial hardship. Diane is keenly aware of the financial disadvantage of her family situation. She is prevented from earning “big dollars” because of her caring responsibilities, but the carer’s allowance she receives is small and is in no way a wage that reflects the value of the work that she does. She is angry that her carer’s allowance remains low no matter how hard she works. In caring for her son, she has no control over her income. For her, the limitations on the family’s income are a direct reflection of the low value accorded to her son and family:

Diane: You know, you become really ... you don’t need to become negative, but it happens because you’re always fighting for rights, or some decent treatment of your person you’re caring for, or for some ... . Equality’s a good thing. We’re not treated equally.

Carmen: In what ways do you feel you’re not treated equally Diane?

Diane: You’re just not.

Carmen: Do you think William in particular or do you think you also along with William?

Diane: I just think, I just think families who have disabled people in them are the most overworked, underpaid, devalued group of people around. The government first and foremost. The bit that bugs me the most is, “OK, I’ll get a ... I get a carer’s allowance”, but that goes on my husband’s wage. Why? However much he earns does not change my workload with him. I should be able to get the money that his disability requires me to have. The input I need to put into him should govern how much money I get, not how much my husband brings home, cause he’s got nothing to do with my workload with William. I think that’s ridiculous. That is playing on your conscience, they’d say, “Oh they love that child or that human being, they’re gonna look after him. We’ll just throw them crumbs”. Makes me angry, really angry.

For Diane, the restriction in her ability to work and the limits this places on the family income are very much bound up with the disadvantage of having a child with impairment and how her family are viewed and treated.

Families with a child with impairment have been described as facing a double financial jeopardy, in that at the same time as primary carers in these families are restricted in their workforce participation, the families face greater expenses due to their child's impairment (Dobson et al., 2001). Shauna's, Trudy's and Samantha's families fit this description.

The costs of impairment are not experienced in the same way by each family. A parent such as Trudy faces the daily stress of stretching her limited income to meet basic household needs, combined with the significant expenses entailed by her son's impairment. Trudy has some protection from financial stress because her mother helps her with bills, but she faces uncertainty about how she will meet future impairment-related expenses. Shauna too faces uncertainty about how she will afford impairment-specific expenses. And Samantha faces uncertainty about her son's future living arrangements and the amount of financial help they can expect from others, despite having a high income.

#### *Disablism and family financial costs*

I argued in the previous section on constraints on maternal work that the negative consequences for the family of caring for a child with impairment ought not to be understood as solely the responsibility of the family. Similarly, the financial costs of caring for a child with impairment ought not to be seen as solely the responsibility of the family, any more than for any other family. That families feel responsible for the costs of their child with impairment does not of itself prove that the financial costs of impairment for families are or ought to be solely the family's responsibility. As Thomas (1999) has argued, "private" does not equate to impairment effect. The

financial costs of caring for children do not belong solely in the realm of private family responsibility, because the costs of bringing up children are high, and because society in general has a large interest in the wellbeing of its children. For example, employers like to have skilled employees, and the taxes that businesses pay contribute to educating their future workforce (Folbre, 2001). The financial costs of impairment are not discretionary. These costs are essential as are other state-subsidised health and education costs of bringing up children.

The families in this study experienced financial disadvantage, in part as the result of the costs of impairment. One of the achievements of the social model for adult wheelchair users was the recognition that financial hardship was not an inevitable consequence of impairment, and that there was a need to work towards ensuring equal access to paid work for adults with impairment so that they would not fall into or remain in poverty. The social model has also been used as a tool to ensure the sharing of the costs of modifications that allow equal access, rather than allowing the costs of impairment to be privatised to the individual with impairment. So, for example, it is not the individual responsibility of those who use wheelchairs to pay for modifications to the public physical environment such as ramps or lifts.

When the social model is applied to the financial costs for families of caring for children with impairment, it can expose in a similar way the extent to which financial disadvantage is an example of disablism rather than an impairment effect. Disablism is evident when family disadvantage for families with children with impairment entails hardship, lack of choice or uncertainty. Trudy, for example, must have a van to go shopping with her son; other families may choose a van but it is not a necessity. By

the time of the second interview, Trudy's concern about how she can afford to replace her van is increasing. The oppressive quality of the financial disadvantage for families like Trudy's lies not just in the family missing out on routine activities such as shopping if they cannot afford a van, which is in itself a social restriction, but also in the sense of uncertainty, dependence on charity, or lack of choice, that Trudy experiences when she faces replacing her van. These negative experiences – uncertainty, dependence on charity, lack of choice – are not caused by impairment. They are the result of an exclusionary practice that privatises the cost of the van to the family. They also overlap with the negative experiences of poverty.

*When families experience financial disadvantage due to having a child with impairment such that they experience social restriction, uncertainty, dependence, or lack of choice, this is disablism.*

### Restrictions on family leisure activities

Mothers in this study reported restrictions in family leisure activities because of having a child with impairment. Restrictions came in many forms; some families were unable to go on family outings like other families, or, when their child with impairment was unable to go to certain places because of the impairment, the family went only to places to which the whole family could go. Mothers worried that the extra work that they did to support their child with impairment reduced the time they had available for other family members and that this might hurt their other children. Belinda, Janice, Jean, Samantha, Nisha and Diane all said that they feel restricted by the need to care for their child with impairment.

Belinda gave examples of the leisure restrictions that her family face both within the home and when out in the community. Leo, the youngest of Belinda's four children, has a severe developmental delay and a medical condition. Belinda says that there are restrictions in family life because there are some things that the family cannot do together, or that are much more difficult for the family to do together. She says that they often have to split the family, with her staying home with Leo while the rest of the family go out, and thus they do not go out together as a family as much as she would like. For example, the whole family cannot go swimming together, because Leo cannot go swimming because of his medical condition, and they cannot sit together as a family on family outings to the circus, to the movies or the Easter show, because of Leo's large stroller. Overall, family life lacks spontaneity. Belinda says she has to push hard to make a place for Leo, literally and metaphorically, when out with the family, for example by arguing to get seating for him at an event. So Belinda describes the family as experiencing restrictions in how they are able to "do family".

Belinda's response is to encourage the other children in the family to understand Leo's needs so that they do not resent him, to involve all the children in caring for him, and to teach the value of "consideration". For Belinda, it is the family's job to create social opportunities for Leo that currently do not exist for him. She and her husband Jim explain that they do not want others to be forced to include Leo based on an abstract claim for "disabled rights". Rather, they work to create a social environment for him so that other people will "accept" him, appreciate him, and therefore welcome him. So Belinda teaches her other children to take care of Leo, and she also teaches children who visit the home about Leo's special needs, such as how he eats differently to other children, so as to create an understanding community

around him. She plans to set up a disabled cubs group for Leo. She describes how she wants Leo to be received in his local community:

Belinda: So there's a lot of normal groups that [disabled] kids can't get involved in. So we might be starting a new thing, disabled cubs.

Carmen: So it sounds like as he's getting older you'll be on the lookout for those opportunities for him?

Belinda: Definitely. To keep him and not to be out there to try to prove a point, I'm not out there saying "my child's normal" and I'm not gonna make it difficult for people that I'm gonna go "you take him or else", no I don't want that.

Jim: We only want him to go where he's going to be welcome.

Belinda: Well discrimination rights and all this sort of thing, that's not good. It doesn't make him comfortable because he knows, he knows if people are uncomfortable with him.

Jim: I can walk up [town] shop now and know 10 people walking into the shop because it is a smaller area and most of those people know will say "how's Leo going?" or whatever because they're aware of Leo. So I'm really lucky being in a smaller town.

Belinda and Jim want the rest of the community to appreciate Leo. They are satisfied with their strategy of creating an accepting social environment for Leo, although they have also experienced some barriers that they have not been able to overcome, to do with getting services for him - preschool services at the time of the first interview and school services at the time of the second interview. (These barriers are described in the next section concerning family relationships with services.) Belinda and Jim have to work harder than their peers to create leisure opportunities for their child and family, as evidenced by them having to start a cubs group themselves.

Nisha, the mother of Dean, a preschooler with severe developmental delay, says that at home her life revolves around her son such that the home is "Dean's world". Dean is very active, and she needs to supervise him closely, especially if they go out. She

has been unable to go back to work as she did with her older children, and feels that she does not take care of her diet and exercise as she would like. Nisha's feelings of restriction are greater than they were for her other children. Diane, whose son William is a young adult, would like to go out for walks on her own but she cannot leave William alone in the house, and she cannot use the home help she receives to go out for a walk because the helper is not allowed to have responsibility for William. She says, "You don't own your life any more". In fact, Diane says that things get worse as your child with impairment gets older: "They get bigger, your problems get bigger".

Two mothers of adolescents with autism described themselves as restricted to the point where they feel imprisoned because they are limited to the home so much. One of these mothers, Jean, cannot take her son out of the house on her own because he will not do as she tells him and so it is not safe for her or him to go on outings. During the week, she can go out of the house only when her son is at school. The other mother of a teenage boy with autism, Samantha, feels trapped and bored at home.

Having a child with impairment can also be source of opportunities for family leisure as well. Jean, for example, has attended parent support groups at her son's school, but says she is not particularly interested in mixing with other parents of children with impairment. On the other hand, Janice says that most of her family friends are "not normal"; that is, most of her friends have children with impairment. Diane also seeks out and enjoys the social opportunities for the whole family that are available through William's day program.

### *Disablism and family leisure activities*

The challenges described by mothers in this study to being together as a family, whether in the home or when out, are consistent with other descriptions in the literature of family life with a child with impairment. Parent concerns about family social restrictions and their reduced time and attention available for siblings have been reported in many studies (e.g. Hornby, 1995; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008; Olsson & Hwang, 2003). Family strategies of splitting the family or forgoing activities have also been described (Mactavish & Schleien, 2004; Schneider et al., 2006).

Dowling and Dolan (2001) interpreted the differences between the social opportunities of families with and without children with impairment as evidence of disablism, as described in Chapter 3. Thomas' model, however, involves distinguishing restriction that is an impairment effect from restriction that is the result of exclusionary practice, a distinction that Dowling and Dolan did not make. Many family restrictions in leisure belong in the realm of impairment effect. Children with impairment do face particular social restrictions as a result of their impairment, families with a child with impairment may find the leisure options in which all family members can participate to be more restricted than other families. For example, Jean's son finds that places such as shops can be overwhelming, and Jean cannot take him out on her own because of this. Mactavish and Schleien (2004) described the challenges in finding suitable activities and in organising their members that families with a child with impairment face. Sometimes a parent will stay home with the child with impairment if the activity that other family members are doing is not suitable for that child. For example, when Belinda stays home with Leo while the other children

go swimming with their father, this is a sensible arrangement in the light of Leo's impairment, and can be understood as an impairment effect, rather than as disablism.

A family deciding not to do an activity when an activity does not suit the child is not necessarily evidence of disablism. Differences between the recreation of families with and without impairment are not automatically evidence of disablism, because impairment too shapes the possibilities open to families. Indeed, to assume that the recreation of the family with a child with impairment should be the same as that of families with typically developing children risks imposing an inappropriate standard on families with children with impairment (Cummins & Lau, 2003). This may invalidate the differences that impairment brings to their family life that are legitimate ways of "doing family", that just look different from the way that other families do family recreation.

However, as Thomas described in her consideration of the distinction between impairment effect and disablism, a restriction that is an impairment effect can also be a marker for a restriction that is the result of disablism, and the two can be intertwined. Thomas suggested that disablism is evident if a person with impairment is prevented from doing things in an unorthodox way, or is prevented from accessing technologies that would enable them to do things that other people do. When this logic is applied to families with a child with impairment, the use of respite care by families to do things that they cannot do with their child with impairment can be seen as an "unorthodox" way of doing family. For example, Janice described using the time when her son was in respite care to take the rest of the family to places that she found it difficult to go to with Stephen, such as the zoo. In a similar fashion, the

example that Dowling and Dolan (2001) give of a family not going to the cinema because one of the family members has autism may also be understood as an instance of impairment effect. As long as the young man with autism has other leisure opportunities and other family members can go to the cinema at another time, the family being unable to go to the cinema together is not disablism.

For Thomas, disability and impairment effect occur together, but it is important to distinguish between them so as to identify disability as the priority for social change. The yardstick by which to identify disability is to identify evidence of the unequal and oppressive relationship of disability, rather than in this instance to assume that family leisure must be the same for all families. Some families with a child with impairment seek and enjoy “special” networks; their way of “doing family” may be unorthodox, in that their social networks or recreation patterns do not look the same as those of families with typically developing children. If they do not mix with families without children with impairment, or engage in recreation and leisure activities in the same way as “normal” families, it is not necessarily evidence of disablism. The difference becomes disabling if the family with a child with impairment experience little or no choice in their leisure opportunities, or barriers to accessing an activity that does suit them.

*When families experience barriers to participating in leisure activities, and taking into account family activity restrictions that are impairment effects, this is disablism.*

## Family relationships with services

Families with a child with impairment are often involved with many health, disability, and social services, and typically rely on these services in a way that other families do not. Despite an intention to assist, services can work in ways that can produce or reproduce disability for families with children with impairment.

Before considering the ways in which services disable families, it must be acknowledged that services can also be a source of gain for families. Having a child with impairment is an entrée into a world of services which families would otherwise know little or nothing about. Contact with services can be affirming for families and can extend their support network. For example, the service providers that Nisha met were very important to her, because they helped her to take care of her child:

I think the struggles of trying to get the best you can for your child whether it's therapies or services or whatever, that's been a struggle, but you come across people that have been helpful and you can never be thankful enough for those encounters.

This contact with the world of services has also influenced Nisha's daughter, who as a senior high school student has seen the work that early intervention workers do with her brother, and as a result is interested in becoming an occupational therapist. Diane is critical of many of the services with which she has had contact, but at the same time she sees that some workers have been a great resource for her son and her family:

We got into distance ed. Totally different kettle of fish. Supportive, incredible people who thought about not just the person with the disability but the whole family.

Maureen, Yuki, Belinda and Nisha all used early intervention services and were satisfied with their children's therapy services. This may reflect the priority that services give to early intervention. This is not to suggest that for parents of young

children getting services is necessarily straightforward. Nisha, for example, is satisfied that her son Dean, who has a severe developmental delay and epilepsy, is progressing as well as he can, but she was unhappy with the initial assessment and lack of service offered by the disability service. Dean was initially classified as not severely impaired enough to qualify for a certain level of early intervention service, and Nisha had to make a formal appeal to the service to have that decision changed. Nisha worried that other parents of non-English speaking background whose English skills were not as proficient as hers would have even more difficulty in securing services. She thought that the initial assessment was made because she had presented herself as coping well and not in need. When she appealed the decision, she felt as though she was begging, but that she had to do whatever it took to get a service for her son. She learned from this experience not to present herself as coping too well in case her son's services were reduced.

There were a number of instances where parents felt that the process of seeking help meant that they had to demean themselves to secure a service. Service resources are limited, and so are rationed according to various criteria of child and family need. When parents perceive that services are allocated on the basis of demonstrating their need, they may emphasise their problems and their inability to cope in order to secure a service, as Nisha discovered. Samantha described how difficult she found exposing the family's struggles to a service provider, because it felt like confessing her failure as a parent:

They need to be more receptive on the subtle cues people give. You know, really you have to be a sledgehammer. I don't think anyone really wants to – well, in our position I don't really want to accept government help – you want to do it on your own, things like that, ... but if you're used to doing it on your own, also, that sense of privacy, and pride, and – you know you really have to lower your pride a lot to have to go and say, "We can't do this any more".

Because that's a horrible thing, it's like, almost rejecting your own child, so, it means you're failing.

These experiences of parents feeling obliged to demonstrate their neediness, feeling that they need to demean themselves or present themselves in an incompetent way, suggest a problematic imbalance in the relationship between parent and service provider. At the very least, the relationship is unequal, in that the decision of what to provide is made by the service (and service providers are not required to demonstrate their incapacities to parents!). Services may inadvertently encourage the expression of or adoption of dependent, needy or demeaning roles for parents.

Perhaps unsurprisingly, given that parents must demonstrate their child's or their own need in order to qualify for services, families can also feel that they are judged as needy by service providers. For example, Jean reported that she felt that some of the workers who came to her home looked down on her. Jean was obliged to allow the service providers into her home if she wanted the service for her son, even though this exposed her to their negative judgment. When services are provided in their home, there may be an extra dimension of intrusiveness for the parent to this perception of being negatively judged. Diane also complained about a worker who thought she should be grateful for her services:

She was saying, "You be grateful. I've come in here, you be grateful. Lick my boots". I don't be licking nobody's boots, because I'm giving someone a job, aren't I? So if we look after each other and get on well with each other, everything's hunky dory. I don't like that attitude, you know, this greater than thou attitude because – I don't like attitude.

Diane objected that the relationship that the worker presumed between them was not equal or reciprocal.

Mothers often reported that services were unresponsive. In particular, the parents of the young adults in the study group were unhappy with extensive waiting lists and restrictions in therapy services. Diane, for example, was unhappy about how little therapy service her son received, and felt that that her family's needs were not recognised and their legitimate requests ignored:

I don't like being put on waiting lists indefinitely, because I don't ask for much help. And I think dedicated parents don't. When dedicated parents ask for some support, they want it or they need it. You know when we're on the phone every other week, and we say "Could we please have a check up" or whatever, we need it. So that we can keep going the way we're going.

Janice, who is the mother of a young adult, made the point that service shortages and waiting lists were not the fault of individuals, but rather of how services are set up and resourced. She complained that there were long waits for therapy services, and that not all the allied health therapies are even offered for people her son's age. She was careful not to blame individual therapists for this: "It's the government's fault, not theirs".

Janice, Samantha and Diane were concerned about the quality of services as well as their quantity, and about their inability to influence services to improve. Janice criticised the quality of the day program that her son attends, because he is not always fed or changed while he is there, and he is not always positioned properly when he travels. Janice has tried to correct these problems ("every now and then I go on the warpath") but she is resigned that her son will continue not to be treated well consistently. Janice is also unhappy about the quality of the care provided in her home by one of the personal care workers, who is insensitive and rough in handling her son. She had accepted this carer being rostered to care for her son occasionally, but he has been rostered on to care for Stephen much more frequently than Janice had initially

agreed to, and she feels she has no choice but to accept the roster given by the service that has this carer coming to her home much more often than she had initially agreed. She has tried to tell him how to handle Stephen nicely but the carer does not listen, and she feels she is stuck with him. Altogether, Janice is fairly pessimistic about her ability to influence the quality of services and feels she has little choice but to accept what she is given.

Belinda's experience of the quality of schooling her son was receiving that she reports in the second interview provides another example of the way in which the quality of service affects both the child with impairment and their family. Leo was crawling and pulling himself up, and Belinda hopes that he will learn to walk. For him to develop the skills to walk, he needs to be on the floor. However, in his school class he is kept up in a chair most of the day, because, despite the small number of children in his class, the teacher cannot supervise him if he is on the floor. Belinda described the school as "struggling" and under-resourced for the needs of the children, and she visits Leo's classroom regularly to assist the teacher and Leo. She thinks that the school is unable to give Leo the program that would maximise his chances of learning to walk.

Having to rely on services can also subject families with children with impairment to intrusive scrutiny. During one of my interviews with Samantha, she suspended the interview when her son's respite carer walked into the room while we were talking about family relationships. She later explained that she had heard the worker talk indiscreetly about other families and worried that the worker would gossip about her family as well. Samantha does not like having respite carers in her home, because of

the loss of privacy, and prefers respite to be provided out of home. She really likes the out-of-home respite they get, but thinks that there is not nearly enough of it and that she has little influence over when and how it is allocated.

The organisation of daily life for families depends on the kind of activity available for the child or young person with impairment. When a service cannot or does not provide what parents feel their child needs, this may create uncertainty for families, or, conversely, create extra work for the primary carer who steps in to fill the gap in the child's care. Belinda provided an example of this when she went to her son's school regularly so as to assist the teacher to provide the right program for Leo. Belinda also experienced a barrier to participation earlier when she tried to secure a place for Leo in the preschool his older siblings had attended. The preschool director was reluctant to enrol him and only accepted him on condition that Belinda went to the preschool to feed him, as he is tube-fed. Belinda found this enormously frustrating because she lost a rare opportunity to have some time for herself, but, above all, she thought her child was unfairly treated and that different rules were being applied to him. She said: "If the preschool can't guarantee his safety, then they shouldn't be operating, he's no different to a 12-month old baby in what he does". Belinda wanted her son in a regular preschool, but his placement there was uncertain and she had to work hard to keep him there. She had little power to influence how decisions were made about her son's placement in preschool, and she felt frustrated, angry and powerless as a result.

The negative impact of services being inconsistent or uncertain is also seen in Jean's story. Jean's son Kevin has autism, and goes on outings with a support worker. Jean

values this service, especially as she is unable to take him out on her own. However, this service can start and stop at short notice, depending it appears on when funding runs out, which to Jean is very unclear, and unrelated to her need for the service. At the time of the second interview, Jean is also waiting to hear whether Kevin has been accepted into the one local day program that might be suitable for him next year when he leaves school. It is up to the program management to decide whether Kevin fits the program, and Jean is worried that he will not be accepted, because he can be very challenging and it is the nature of his impairment that he does not “fit in” with others easily. If he does not go to that program, Jean is uncertain that there will be anywhere at all for him.

Samantha also makes the point that services do not respond to family need, and may exclude families without any assurance that any other service can help. When her son Peter was about eight, he became increasingly violent, and services withdrew because of his difficult behaviour. At the time the family most needed help and were in crisis, services withdrew and left them on their own trying to deal with their violent child. Peter’s violence scared his mother and his siblings; Samantha had to tell the other children to run and hide from Peter, and she herself hid bruises and did not want to leave the house, because she did not want to have to explain to anyone that her son had hit her. From Samantha’s perspective, services contributed to and increased the crisis that her family were experiencing, because as these services withdrew, she was left with no assurance that there was a service that could help her or her family.

Although Peter’s behaviour is more settled now, the sense of uncertainty about his future, and the memory of the trauma of that family crisis, remains for Samantha.

When I asked Samantha about how she saw the future for her son, she replied, only half joking, “You tell me”. Samantha criticises services for being piecemeal and ad hoc. There is no future plan for Peter, which contributes to her sense that the future is bleak, that only her family has any responsibility for Peter, and that her family cannot rely on anyone but themselves.

Past experience of service responsiveness and reliability colours how parents think about future service options. In contrast to Samantha, Trudy is confident that if she is no longer able to care for her son there will be a service that can take over. Trudy found that when she needed respite care because she was starting to resent her situation, her disability services case worker listened and organised respite promptly. Laura, who works for a disability service, is confident that when Tianne is an adult, there will be a service that can care for her: “There’s perfectly good places out there”. On the other hand, Diane, like Samantha, sees services as unresponsive to her family, and this influences how she sees the future:

What happens to him if we leave? I haven’t got a clue. It frightens, it frightens me to death. I don’t think he would last very long anyway, I think he’d fret to death for either one of us, but it’s scary. It really is, when you don’t have support and the understanding, and I don’t like it. It’s scary.

No parent or family can be certain about the future, but these families face particular uncertainties because of the limited living options available for their children with impairment. Parents imagine that their child will be with them indefinitely, because there is so little accommodation available for adults with impairments, or because they question the quality of what is available, whereas parents of typically developing children can imagine that in the future their child will live independently. Caring for their child indefinitely presents particular uncertainties and potential burdens for

parents, such as Diane's worry about what will happen for her child when she is no longer able to care for him. Diane worries that in the future her child may have to rely on a care service that her experience has told her cannot be counted on to provide quality care.

A common theme in these mothers' accounts was feeling discarded or abandoned by services that do not understand their needs. Mothers reported feeling unheard when services seem uncertain, inconsistent or unresponsive. Parents were put on their mettle when they were forced to rely only on themselves. Jim and Belinda, for example, have had to work hard and rely on themselves, despite multiple services being involved with the family:

Jim: I'm saying we've done the hard yards early, right, we've done everything ourselves, but a lot of people, if it's thrown at them ...

Belinda: Well they're entitled to it they use it, Jim, it's as simple as that. It's got nothing to do with that. But if I ... so many times, oh god yeah I could have done with some help.

Samantha found that the way services work added to her pessimism about her family's future life: "No future, no, not adequate planning. No future really. That doesn't depress me now, I just accept that". Family experiences that services are nonexistent, inconsistent or unresponsive make families rely on themselves, and when families feel that they have resources, their sense of competence as a family is reinforced. When families feel that they cannot cope on their own, the experience that services are unresponsive reinforces the family's sense of helplessness or hopelessness, as evidenced by Samantha's comment.

Relationships with services can be fraught when parents feel that they are powerless or have little influence. One of the major frustrations that parents felt that runs

through their accounts is the sense that there is little that they can do to persuade services to provide what they want for their child, and that what parents want for their child and for their family does not determine what is actually provided. Concerns described by mothers in this study about services are consistent with many other studies that report that despite the widely accepted policy of family-based practice (Leiter, 2004; Read, 2000) and its demonstrated value in facilitating parent-professional communication (Dunst et al., 2007; Keen, 2007), parent dissatisfaction with services is frequently reported (Case, 2000; Dowling & Dolan, 2001; Lundeby & Tossebro, 2008; Redmond & Richardson, 2003; Todd & Jones, 2003). Mothers in this study wanted flexible and responsive services that listen to what they want, which is consistent with surveys of parent needs (Case, 2000; Prezant & Marshak, 2006).

#### *Disablism and family relationships with services*

Thomas' description of disablism as based in an unequal relationship is evident in family descriptions of their experiences with services. As with other aspects of family life with a child with impairment, differences between families with and without children with impairment are not in themselves evidence of disablism, and contact with services is not inherently disabling. However, there is evidence that the relationship between parents and services is underpinned by an unequal power relationship consistent with the social model (Clear, 1999; Dowling & Dolan, 2001; Woodcock & Tregaskis, 2008).

The mothers' accounts, especially from mothers of older children, attest to the lack of an equal and collaborative relationship with services; they felt they had little or no power to influence services, and they did not feel that they participated equally in shared planning and decision-making. Diane, Jean and Samantha reported experiences

of loss of privacy and negative judgment through contact with services. Nisha felt as though she had to beg to secure early intervention for her son with a severe developmental delay. Belinda was unable to secure a place for her son in the preschool that her other children had attended, no matter how hard she worked to obtain it. Janice felt she had to accept the service given to Stephen, even though it was not good enough. Jean's highly valued respite service stopped and started regardless of her wishes. Samantha felt that the future was unknown and bleak, and much of this, she thought, was due to service inadequacy. Trudy seemed more confident about her family's future, but this was very much dependent on services being able to step in and care for her son in a timely way.

Parents are not able to simply opt out of dealing with services when they feel not listened to, negatively judged or demeaned. They depend on services to assist them and their child, and so they must interact with services. These experiences all attest to a system of service provision in which parents are not equal partners and have little or no control.

*When family members of families with children with impairment are obliged to interact with services which do not recognise them as equal partners in planning and provision, as evidenced by parents feeling they have little or no control over services, feeling intruded upon, uncertain or devalued, or feeling that they have to act in demeaning ways, this is disablism.*

## Conclusion

Restrictions in family life have been described in the areas of mothers' participation in paid employment, family financial situation, family leisure, and family relationships with services. There is evidence of disablism in family life when these restrictions are the result of an unequal social relationship that takes little or no account of the needs of families with a child with impairment, and which results in lack of choice, uncertainty, dependence, powerlessness, and parents acting in ways that they do not desire. Therefore the part of Thomas's conceptualisation in which disablism results in material barriers holds true for families with children with impairment. The material barriers in the lives of families identified in this study lead to the following theoretical propositions:

*When mothers of children with impairment are unable to perform paid work, and when this restriction is not an impairment effect, this is disablism.*

*When families experience financial disadvantage due to having a child with impairment such that they experience social restriction, uncertainty, dependence, or lack of choice, this is disablism.*

*When families experience barriers to participating in leisure activities, and taking into account family activity restrictions that are impairment effects, this is disablism.*

*When family members of families with children with impairment are obliged to interact with services which do not recognise them as equal partners in planning and provision, as evidenced by parents feeling they have little or no control over services,*

*feeling intruded upon, uncertain or devalued, or feeling that they have to act in demeaning ways, this is disablism.*

## *Chapter 6*

### *Non-material restrictions and disablism*

#### Introduction

Thomas has argued that disablism also reaches beyond the realm of the material to incorporate psychological and emotional dimensions limiting how people with impairment think and feel about themselves. These restrictions Thomas termed “barriers to being”. This chapter outlines the extent to which Thomas’ concept of barriers to being applies to the experience of families with a child with impairment.

Before considering family experiences, I briefly review Thomas’ concept of barriers to being. Barriers to being are disabling barriers or restrictions on the psycho-emotional wellbeing of individuals with impairment that are the result of the action of “prejudicial meanings, ideas, discourses, images and stereotypes”, whether conscious or unconscious, along “psychological and emotional pathways” (Thomas, 1999, p. 46). Prejudice in its various manifestations restricts the potential of people with impairment by undermining their psycho-emotional wellbeing. Thomas described barriers to being as a pervasive and powerful threat to wellbeing that requires constant resistance by people with impairment, and argued therefore that this form of disablism requires attention equal to that given to the more obvious socially imposed material restrictions of barriers to doing.

## Encounters with prejudice

Mothers described encounters with people who held negative views about their child with impairment. Trudy, the mother of a 12-year-old with severe intellectual and physical impairment, described how a stranger advised her to institutionalise her child:

I mean I must admit one day somebody said to me – Oh what physical disability, what disability has your son got? And I said – cerebral palsy. And she said – I don't know how you do it. Why didn't you get him institutionalised? [...] You know, why didn't you get him? And I said – Because he's my son. I said – Would you get your child institutionalised? She said – Well if he had a physical disability, yes I would. And I went – That's your prerogative. I could feel my temperature sort of going higher and higher and higher.

This stranger felt entitled to share her views, did not seem to sense that they were offensive to Trudy, and clearly felt that a child with severe impairment was obviously inferior to other children, to the point where that child should not have a family like other children and should be discarded. In this person's view, the impairment of the child overrode any other consideration and justified the child being treated very differently from other children. The attitude of this person cannot be claimed to be typical, and Trudy certainly said that for every unpleasant encounter, she experienced other people wanting to be kind and generous to her son and her. But this encounter nevertheless demonstrated for Trudy the way in which her son was seen by some others as defective and as warranting discarding.

Encounters with unkind strangers can also affect other family members. Laura recounted how her oldest daughter came home from the park crying because a young boy at the park was teasing her sister by calling her "spastic", while the mother of the child did nothing to correct him. This encounter reinforced for Laura that unkind

attitudes about impairment exist, and that at times negative attitudes will be expressed towards their family member with impairment. Belinda also worried that her other children would be teased about Leo's impairment. Nisha worried that prejudice about her son having a genetic disorder would lead others to think that there was a problem in the family, and that this might affect her older children's marriage prospects.

*Prejudice attaches to the family as well as the child*

Mothers encountered negative attitudes towards impairment that extended to the family as a whole. Negative prejudicial judgment about a child with impairment can also contain, either implicitly or explicitly, a negative judgment about the family as well. For example, in the encounter experienced by Trudy outlined above, the woman who told her that she would institutionalise such a child was also telling Trudy that Trudy's judgment was poor since she did not do so, and was suggesting that not only was there something wrong with the child but also there was something wrong with Trudy for keeping such a child. Trudy did not agree with this person, but she was nevertheless affected by the encounter because she felt very angry.

Mothers reported that their child and they as a family were judged as wanting, or as being damaged by having a child with impairment. For example, Maureen said that one of the hardest things about having a child with impairment is going down the street to do her shopping with her 4-year-old son Danny and being asked by strangers what is "wrong" with him. When she tells them about his chromosomal disorder, they offer her pity because she does not have a normal child: "They immediately jump on the pity bandwagon". Maureen rejects their pity because it is based on the misguided idea that it must be terrible to have a child who is not normal. She explains her situation and corrects misperceptions:

A lot of people will come up and ask you about it and you sort of, you know, you'll launch into your whole pre-prepared speech pretty much of, you know, of well this is what he has, and this is how it affects him, and all that sort of stuff and, "oh you know, you poor thing". And I'm like, "Well don't feel sorry for me! You know don't, please don't". He is – like and I've sat there in the middle of a shopping centre or supermarket or whatever and given people a lecture on you know, "don't feel sorry for me", because, you know, my son is beautiful no matter how he is, you know, and people's perceptions of it are really hurtful sometimes, you know, and that's what makes it hard a lot of the time because, you know, people say "Oh well how do you cope not having a normal child?"

Maureen does not accept the prejudiced views of others, but she finds them hurtful and avoids situations where she thinks she will be exposed to these attitudes:

I mean Danny doesn't really pay any attention to it because he doesn't know. If people stare at him he just thinks it's funny (laughs). But, you know, you just, you feel like a leper, like you've got a big, like you're carrying a plague or something, you know, so I tend to sit close to home, I socialise with people that I know, that know me, you know my friends and stuff, that don't care about things like that because they see beyond that.

On the other hand, Belinda feels the response of other mothers she meets is compassionate:

Belinda: But you know actually I think society has come a long way but, because I mean I remember myself, as a child, and I saw a child that you just didn't see out, you never saw them out, you know, for that reason, because mothers kept them at home, or they were in homes. But I think society has come a long way. I think so, even in the short time I've had Leo, you know. I find that I get a lot of sympathy, compassion, rather than a freaky compassion, you know what I mean?

Carmen: Like so nice compassion, just the understanding that you've got, kind of thing?

Belinda: Well "I kind of feel for you, yeah, I understand what you might be going through, I'm a mother myself, I'd hate to be in that boat". So I get more that. Like Leo got invited to his first birthday party.

Carmen: Yeah. So it's not saying, so it's not saying something nasty about Leo.

Belinda: No. I think 10 or 15 years ago there was a lot of finger pointing, a lot of giggling and a lot of, and I think it's to do with the way society is now accepting children out. And I think it's, like 20 years ago facilities weren't

around, and I'm thinking as time's going on, community are accepting children. Like now Leo is now at the mainstream preschool. He is inputted on all those children at school that are normal. So that is starting their life already beginning to understand that other people are different. Where when I went to preschool, which I don't think I ever did, but they wouldn't have had a child like that at school. And I'm thinking that society is accepting children more, allowing them to become more involved. Like they've camps and they've got things that they just didn't have 15 years ago. And I'm thinking as they're getting more accepted, people understand more about these people, that they realise, you know, they're not these freaks, it's not their fault, or whatever.

This reflection from Belinda contrasts with the experience of Maureen, who was incensed by the pity of others. Maureen reacted angrily to the pity of others who judged her child and therefore her own lot as inferior because her child was not "normal". Belinda thought it understandable that another mother would not want to be in her position. Belinda put her acceptance of the pity of others in the context of what she saw as an increasing social acceptance of people with impairment.

Negative stereotyped ideas about impairment can also influence not only how individual family members are seen, but how the family as a whole is seen. Janice worked to protect her children from being harmed by and being seen to be harmed by having a brother with impairment. Janice used to worry that if any of her now adult children had problems when they were younger, it would have been attributed by others to their having a disabled brother. This concern motivated Janice to make sure that she made up for the things that her nonimpaired children missed out on, for example by using the time when Stephen was in respite care to take the other children to places they could not go with him. She also did not give the other children responsibility for Stephen's daily care, because she saw that as her responsibility. She worked to create a sense of family by having the children visit Stephen in hospital when he was sick and on occasion had them attend the hospital school together with

him. She was confident that she gave the children enough attention and that they did not have too much responsibility for Stephen:

But I've tried to over the years with the kids not to disrupt their lives too much, you know, cause I don't want in years to come have people say they're like that because of Stephen. ... At times they did [miss out]. But then I made up for it at other times. I felt that I did.

Diane thought that both she and her son were treated negatively because her son had an impairment, and she thought this was part of a more general devaluing of children with impairment and their families. She thought she was seen by others as incapable:

It's hard living the life we live. It's really hard. You're devalued as a human being. You know, like ... just because I had William who's got a disability, people presume I've got a disability too and treat me like a fool. I don't like that.

Diane said that her husband George was also devalued, and that she had to remind him not to believe the negative things other people said, because she thought George was vulnerable to believing negative things about himself (but not about his son) because of having been mistreated by his own family. Diane thought that the way he cared for his son countered the devaluation of others:

You know, I just get such a high out of it. I really like, you know, and George does too, you know, we just love it. We just really love it. Yeah. They don't have, they don't have rights and we don't have rights either. We're devalued and trashed on all the time and I don't like it. I don't like it at all. Nobody ... people come along and say to George, "You're only this and you're only that" and George will say "Yes, I'm only this" and he'll come home and say it to me and I'll say "No you're not, George. You're a dad, you're a good dad. You're doing a job that someone else can't even do. You know, we do it well, so don't go away thinking that you're not an OK person because you are". And I won't be devalued, because not everyone can do this. Not to the degree that we do it.

Diane described the family as a whole as experiencing and having to respond to negative and devaluing ideas about impairment.

### *Encounters with services*

Families may also encounter service providers who hold negative views about people with impairment and their families. The disabling role of services in erecting barriers to doing was outlined in the previous chapter. In this section, the influence of negative attitudes when communicated by service providers to families is described. I suggested in the previous chapter that there is a power differential between services and families. If a service has greater power than a family, such as when a family depends on a service for help, then the negative ideas of a service provider may do more harm to the family than the prejudiced ideas of members of the general public. Trudy was able to dismiss the prejudiced ideas expressed to her by a stranger and have no further contact with that person. Parents may have to rely on services and therefore maintain contact with them, so they are not as free to avoid whatever prejudice they experience through contact with them.

Jean, who has a son with autism, described how she has been hurt by the attitude of some of the respite carers who have come to her house. She said that she has felt criticised and that they were “looking down on you”. “And you already feel put down enough when you have children like that anyway, don’t you?” she added. Diane, who is very aware of negative judgment of her son and her family, also criticised some of the carers who had come to her home, who she felt thought “there’s places for people like him” and that she should be grateful for the help she received. She ended up telling them not to come. Nisha also talked about the negative attitudes she had encountered as part of the struggle she had to find a preschool for Dean. When she phoned to enquire whether a particular child care service accepted “children with disabilities”, the director of the centre said “no” and hastily hung up. When she did

find a centre that enrolled Dean, staff complained about him making them tired (even though they received extra funding to support his placement there). She was also offended when a staff member told another child by way of explanation of Dean's impairment that he had a "part of his brain missing".

Families also experience positive relationships with service providers. Mothers spoke warmly about service providers who had helped them. Jean talked about how she valued and respected the carers who now came to her home and took Kevin on outings. Diane described how good carers become like family, and Nisha also talked about how grateful she felt for the contact with those who had helped her. Nevertheless, there is evidence in the accounts of Nisha, Jean and Diane that at least some service providers expressed negative attitudes about impairment, and that this had an impact on the family. Nisha, Jean and Diane felt hurt or angry about the prejudice expressed. Prejudice could also implicate the family as a whole, as for example when Diane felt that she was expected to be grateful, and when Jean felt "put down".

#### *Encounters with the negative attitudes of other family members*

Negative attitudes can also come from closer to home, from other family members. This is challenging for family members who see their child or themselves as disparaged, since families are supposed to be a source of support. So although Diane complained about negative attitudes towards impairment coming from many sources, she was most distressed about such attitudes when they came from other family members. She said that her brother is not understanding and accepting of her son, and that her husband's family see her son as "not proper and whole".

Similarly, Jean describes how her mother-in-law struggled to accept her son's diagnosis of autism:

Yeah well Ken's mum did it a bit too. She's not too bad now, but when Kevin first got his problems, she said to me – Oh there's nothing like that on our side of the family. You know. And that always sticks in my head, you know. It's funny people can say things, they stick in your head, don't they? ... But she's always been a person that, they tend to their family, they don't, oh I don't think they're as accepting as my family in some ways, you know, sort of, you know. They sort of want everything perfect and, you know, that type of people.

Jean says that at Christmas time her family are “outcast” because they do not join in a long and extended family celebration. She explains that this feeling of being outcast is in part to do with the lack of interest shown by her own family in her son:

Jean: And then I also felt a bit guilty 'cause I thought, well we're sort of keeping his family, you know, like cutting them up a bit. And we sort of said well we could have it home and come another day, and you could all have a Christmas together. But Ken's mum said no, that didn't matter, because the married sister, she tends to go to [town] anyway, to his family, and the other one, she tends to go down to the auntie's, which is just down the road from Ken's mum's in [suburb]. She tends to go there anyway, cause she's sort of on her own and she has her and her friend and maybe the auntie's boyfriend might come down, and a couple of other friends, and they have a bit of a do there, you know. So apparently they all were happy with that, you know. But you do go through, you feel guilty. You don't want to, you know, split people up sort of, you know.

Carmen: Yeah. And you don't want, you don't want Kevin to be I guess blamed in any way?

Jean: Yeah, that's right. And I sort of feel like, well I often think, oh well we'll have it home. We're sort of outcasts anyway. So, I feel like an outcast most of the time. And I think, oh well, we can all be outcasts together, you know.

Jean's family may avoid contact for reasons other than Kevin's impairment. That her immediate family do not participate in Christmas as fully as she wants may also be due to impairment effect that restricts where and for how long they can go to a Christmas party as a family. However, Jean's repeated use of the word “outcast” is strong language. She is disappointed that her wider family exclude her, and it seems

to reinforce her sense of her immediate family being different (“we can all be outcasts together”) at least in part because her son is different.

#### *Negative attitudes within the parent*

Some parents commented that they had held negative views about impairment, or had not thought about impairment, before they had a child with impairment. For example, Trudy noted that she had no contact with disabled people and had not really thought about it before having her son. Belinda also remembered that when she was pregnant with her son, who has severe developmental delay, she met a friend who had a daughter with severe cerebral palsy. She remembers thinking at the time that she would not cope with that. Belinda also experiences the reaction of other mothers to her as compassion rather than as something more disabling or prejudicial.

### Impact of prejudice about impairment on families

#### *Families have to respond*

Families have to deal with negative attitudes about their child or themselves to the extent that they have to at least respond to negative attitudes, beliefs or ideas when they encounter them. Such encounters reveal the disrespectful nature of some of the ideas that others hold about the child with impairment and their family. Family members will not necessarily agree with the prejudiced ideas they encounter, as for example when Trudy dismissed the ideas of the stranger who told her she should institutionalise her child as ignorant, or when Laura’s daughter cried about her sister being teased. But even in dismissing the prejudiced opinion of others, family members have to deal with the prejudiced ideas of others to the extent that they are forced to notice and respond, and they may well feel hurt or angry. The child with

impairment is seen in these encounters as in some way less than a normal child, and the family is seen as damaged in some way. So Maureen understands that she receives pity because her child is seen by others as a “problem” for her. The relationship between families with a child with impairment and others is asymmetrical, in that the judgment of inferiority or abnormality flows in one direction; families with a child with impairment may receive such judgments, but they do not offer pity to other families for having a normal child.

Mothers may feel hurt or angry because they feel that they and their child are not understood, appreciated or accepted by others as they would like. Mothers may feel that they are not seen as they would like to be seen. Diane, for example, works hard to care for her son, but she thinks very few people value her for this. She feels that her family is devalued and that social values need to change so as “to get that compassion and respect back”.

This sense of not being understood by others is a double-edged sword for family identity. On the one hand, when families feel that they are not understood they can feel isolated and that they can only count on themselves. On the other hand, this sense of being on their own can also reinforce the family’s sense of their competence, independence, and self-reliance. Diane and her husband know what they have to do to care for their son and just get on with doing it, and they feel satisfaction that they do it well by themselves. Similarly, even though Belinda and Jim receive a number of services for their young son, they feel that he is going well because of their efforts: “We’ve done it all ourselves”. Diane’s family surround themselves with other families with children with impairment, whereas Belinda’s family are building networks with

other local families in order to integrate their son into the nondisabled world. Both families have a strong sense of the value of their child and feel that they have to work to build the valuing of their child by others. It may be that all these families see themselves as successfully raising their child with impairment because they have resources within the family on which to draw, such as the mother's commitment and energy.

### *Rejecting and reducing prejudice*

The mothers I spoke to felt angry or hurt when they felt they or their child were devalued. They might challenge the person who was negative toward their child, as Laura did when she told the mother of the child who was teasing her child unchecked to "wake up to herself". At other times, they might dismiss an instance of prejudice as ignorance. For example, Trudy did not show her anger to the person who advised her to institutionalise her child. She thought there was no point because this person was just an "uninformed little twit". However offensive the idea expressed to her, Trudy's sense of the value of herself and her son was not threatened.

Belinda puts a lot of effort into proactively countering prejudice by educating other children about her son Leo and ensuring he is known in his local community. She wants to counteract the prejudice that she knows Leo and his siblings will encounter because of his impairment. She thinks that "there will always be someone who doesn't understand", and this sharpens her desire to protect all of her children. She is proactively educating other people, especially other children, to include and value Leo. She wants them to learn that even though he cannot walk or talk, Leo is fun to be with. Consequently, she has pushed to get him into regular preschool so that he is known and "accepted" by his peers. She shows Leo's feeding equipment to other

children who visit the home so that they will not be alarmed at his different way of eating. She also coaches her other sons not to react angrily if they are teased about Leo. Belinda is concerned that prejudice exists and will be encountered by all her children, and she takes steps to create a valued place for Leo. She worries that prejudice could harm her son's acceptance in the community, but this does not threaten the family's sense of worth or value.

*Describing a normal family life*

Whatever prejudices they might have held prior to becoming a family with a child with impairment, the mothers in this study had overcome them through the experience of caring for their child. For them, the difference of impairment has become a fact of life, rather than, as they might previously have understood, an exception. Mothers may describe aspects of their family life that to an outsider might seem distinctly abnormal as routine. Trudy describes her daily family routine as like any other, even though some of the things she has to do are not typical for the mother of a 12-year-old:

It's no real difference to any other family routine, except that it's more hands on and more intensive. That's basically it. I mean, you still have to get up in the morning, have a shower, clean your teeth, get dressed, have your breakfast, get his schoolbag packed, go off to school. I mean with Matthew it's a little bit more intensive than that because he's not able to do anything for himself. So he needs someone to do everything like that for him.

The difference of impairment has become a normal part of family life. When Janice described the good relationship between her son Stephen who has severe physical and intellectual impairment and his siblings, she said that their relationship is good and that "we're all quite stupid with him, 'cause he laughs at us". Even though Stephen cannot talk, and his communication in general is limited, Janice's description of the quality of his relationships with his siblings emphasised the normality of those

relationships rather than his atypical communication skills. Mary too described her children as getting on together like any other children.

### *Understanding the difference of impairment*

Mothers also described their child with impairment in ways that present their child in a positive light, or in a way that challenges the idea that the impairment is their child's defining feature. They may do this in conscious reaction to the prejudices of others, or it may be their construction of their child. Take the earlier example where Trudy describes her family routine as normal, even though her son can do very little for himself: by describing her experience this way Trudy is protected from being wounded when she encounters prejudice. She sees her family routine as like that of any other family, so her sense of the worth of her family is not perturbed by the prejudicial idea of someone else that she should institutionalise her son.

Belinda compares understanding her son's impairment to understanding the dietary preferences of children:

Carmen: You taught them a bit to include him so he is one of the family that way?

Belinda: Definitely. Consideration, but you do that with any siblings, you teach them to be considerate for other family members. Every family member has a different need. Some like tomatoes, some don't. Like I'm saying everyone is different. So in our case, Leo's different, but to us, it's not...

Jim: He's not a problem. People say "oh, how do you do it?" What do you mean how do you do it? He was made in love, he's love. And that is the way it will be.

By making such a comparison, Belinda is suggesting that having an impairment, even as severe as Leo's, is not so different or unusual, and belongs in the normal realm of

children being fussy about their food. Jim chimes in to support Belinda. They emphasise his capacities and talents rather than his deficits or problems.

There may be aspects of impairment that are less than endearing for families, and are hard to live with, such as difficult, aggressive or destructive behaviour. Parents can nevertheless describe their child without presenting those aspects of impairment that disrupt family life as their family or their child's defining feature. Laura described her daughter with impairment whose behaviour has autistic features as being like a much younger child, in order to explain why she is difficult to manage sometimes: "in her head she's a baby". Jean's son Kevin has autism and his behaviour can be challenging; he screams, breaks things, and cannot sit still for long. Jean emphasised that it's not Kevin's fault that he has autism and he deserves a family even if his behaviour is hard to live with.

Maureen challenged the validity of the distinction between "normal" and "abnormal" altogether. She is frustrated when others pity her because she does not have a normal child, because Danny having an impairment is not such a dreadful thing:

People say "Oh well how do you cope not having a normal child?" and you know, what's a normal child? Who's to say what's normal? You know, so that's what makes it really hard, not so much that you've got a child with a disability because you love them regardless, and you know, it's just people's perception, I think.

Maureen's sense of the value of her family is not shaken when she feels pitied by others, because she does not think her situation warrants pity. Having her son is a joyful experience for her:

I wouldn't change it for the world. And you know, even though it's tough and it's hard sometimes, you just look at those photos. I mean look how happy he is, you know. I wouldn't change it for the world. [...] And even if they had've

done the pregnancy testing on me and done all that sort of stuff, it wouldn't have made a difference, yeah. It would not have made a difference. I still would have gone ahead with the pregnancy and all that sort of stuff. I'd do it again too, in a heartbeat.

Yuki says her son is just as sweet and lovely as any other child, and in fact is much easier to get along with than some of the horribly behaved children she sees on the reality television show "Super Nanny". Yuki's son Luca likes to play on his own, but she says he is like other kids when he does this, and she rejects the pathologising label of "autistic feature" for this behaviour. Jim says of Leo: "Really there's nothing wrong with him", not to suggest that he does not have impairment but that it is not relevant to understanding him as a lovable and important part of the family, rather than as a child with impairment who is therefore different in essentials to other children.

In the examples above, families understand that impairment is not their child's essence. They demonstrate an understanding of impairment that counters the potentially disabling idea that their child with impairment is essentially different from other children. This is not to say that family members are impervious to negative attitudes about impairment. Mothers in the study described being concerned about the way in which vulnerable people in society are looked after in general, and felt that the way people with impairment were treated was one part of the bigger picture that everyone should be fairly treated. Mothers talked about learning tolerance and a wider view, and were concerned about services for others beyond their individual family. For example, Shauna received some respite but she worried that another parent in the neighbourhood needed respite more than she did:

Shauna: But I do have access to respite. A lot of families don't though. When I applied – and a lot less will get it next year too with the funding cuts – and

when I applied for it they were giving packages to 11 families and there were 30 applying for it. So many people miss out, and you kind of have to stop and think then well, you know, do I really deserve it more than someone else?

Carmen: That's pretty tough if you feel you know you have to compare, how needy am I compared with the next person...

Shauna: Well you do. You do when it comes to something like that. Cause I certainly wouldn't want – like there's a woman living down the street who has terminal cancer, she's a single parent has two little kids, and she gets respite for one hour a week. That's it! And she's really sick, and you think, hm, maybe I'm taking the extra money that she could have, but, I don't know. I mean I am grateful when I go out for 2 hours, hands free.

Samantha is critical of the paucity of services and comments that this reflects a more general lack of social concern:

Anyway, but you know, it's not just disability. It's social services across the board. Everyone's become very materialistic and money orientated and we don't look after any disadvantaged people properly.

### *Gains*

Indeed, parents in this study said that there were gains or benefits for their family in having a child with impairment. Some of the gains that parents reported seem to be the joys and rewards of parenting in general. "He's my son, and that's enriching", said Luca's father. Other gains that families reported are specific to raising a child with impairment. For example, siblings of the child with impairment learn that not everyone can walk and talk, and they may be more independent. Mothers also talk about the personal gains for themselves, such as becoming more patient, learning particular skills in caring for their child with impairment, becoming more assertive, feeling capable or feeling that they have a clear purpose in their life. Belinda says that her marriage has improved because Jim has become more involved in caring for the other children, and this has made him more "in touch" with her as well.

Supporting children with impairment can have particular rewards. Because their developmental progress is slower, their achievements, being long awaited and worked for, can be very rewarding. For example, when Leo first climbed onto the coffee table, the whole family went crazy with excitement about his achievement. Maureen remembers the excitement and satisfaction of her son walking in a way that shows that this was a tremendous achievement to be celebrated:

Carmen: Could you tell me a little bit more about I guess the things that make you proud about Danny, things that...

Maureen: Everything. Absolutely everything. He's just – they told us he'd never walk, they told us – you know, all the specialists in Sydney said, you know, don't hold out much hope for what he'll be able to do, and he's walking like he's never had a problem with it, he's starting to talk more ... he's doing things that they said that, probably a 1% chance that he'd ever do. So, everything that he's doing, I just, you know, – the other day he was having – I was having a shower, and he decided that he wanted one too, so took his pants off, took his nappy off, can't get his shirt off quite yet, so I had to help him with that, and he got in the shower and he did a pee. And you know just little things like that, you know, and like he was looking at himself going "Ooh! What am I doing!" (laugh) And you know even silly little things like that, you know, just everything. Every small little thing that he does. He's very smart, he's very smart.

Carmen: You must be very satisfied. You sort of feel, to the doctors, "nyaah" kind of?

Maureen: Oh I do! Absolutely. When he walked, when he walked (laughing) I – like ... When he walked, I was just like, "I told you so!" I couldn't help it, I just ... Yeah, I was just – cause they said that he probably would never walk, and we had to accept that, and I said "No!" I said, "He'll walk!"

Diane's young adult son William is starting to use single words. She said: "He's doing things that nobody ever thought he would, and he's a person that nobody ever thought he would be". Diane feels a particular satisfaction that her child has exceeded expectations, and, like Maureen, shows a certain defiance of medical authority that predicted so little for her child.

### *Affirming family values*

An encounter with negative attitudes about impairment can be an opportunity for family members to affirm their values and beliefs about the family and affirm their commitment to their child. Maureen dislikes going to the shops where people make comments about her child or herself, but at the same time, she takes this opportunity to explain to others that her son is beautiful and that he is a person worthy of respect even though he is not a typical child. Diane objects to the ongoing restrictions in her life that she experiences because of her caring role, but at the same time she believes that she and her husband have grown through having their son:

I just think some people have this perspective of perfection, you know what I mean, and I don't believe any of us are perfect, you know. The only difference is you can see William's, you can't see mine. I do have faults, but mine aren't obvious, and I don't think any of us are perfect, because really, I, I have learnt so much from having him. I'm a heaps, heaps better person for having him and I wouldn't give him away, change him, or do anything with him, because, ... to me, I mean, George and I don't even think about his disability. We work, we know what we have to do, we do it.

In creating a place for their child with impairment, mothers can also find that they need to affirm the value of people with impairment not just to their family but to society in general. Diane says that people with intellectual impairment are clever people, who deserve more respect. Belinda and Jim want their child with impairment to be welcomed at preschool and included by other children, not out of charity or kindness, but because he is fun to be with.

### *Encounters with prejudice do not undermine psycho-emotional wellbeing*

According to Thomas (1999), barriers to being result from the negative impact of prejudice on the psycho-emotional wellbeing of people with impairment. Thomas suggested that "feeling 'hurt' by the reactions and behaviours of those around us, being made to feel worthless, of lesser value" (p. 47) are examples of barriers to

being. In this chapter, I have presented evidence that family members are also negatively affected by prejudice towards their child, and that family members too can feel misunderstood or devalued. Encounters with prejudice can be hurtful and objectionable and affect the whole family.

However, these harms do not really fit with Thomas' definition of barriers to being, in that the process of internalising of negative stereotypes that gives barriers to being their destructive potency does not seem to occur for families, or at least not for the mothers (and two fathers) with whom I spoke. Each mother had a sense of the value of her child and of herself. Mothers might feel hurt in response to the prejudicial attitudes and ideas of others, but they were in no danger of internalising the prejudices of others that they encountered. They did not appear to take in negative attitudes about their child or themselves, and so their sense of their worth was not shaken or challenged in the profound way that Thomas describes for individuals with impairment. As a result, mothers' sense of the value or worth of themselves as parents and of their family as a whole was not damaged or diminished because of their encounters with prejudice.

Indeed, the challenges of having a child with impairment reinforced for these mothers their worth and value. Having a child with impairment could push mothers to articulate their values and advocate on behalf of their child in a way that could strengthen their family. How the families in this study were able to protect themselves from prejudice tells us something important about the "natural" protections that families have or acquire that protect and promote the their wellbeing and that of their child with impairment. Having a sense of the value or worth of the family in the face

of prejudice about impairment is important for these families, because they often rely on services to help them raise their child with impairment. Reliance on services has the potential to challenge the ideal of the independent and self-reliant family. When mothers describe how they as parents work hard and take responsibility for their child, this can justify their reliance on services without undermining their dignity and worth.

Although the impact on families of prejudice seems to be less destructive of psycho-emotional wellbeing than Thomas describes for individuals, I do not suggest that encounters with prejudice are trivial or unimportant for members of a family with a child with impairment. The understanding that there are negative views about impairment certainly matters to families, and they may work hard to protect family members from the harms of stereotype and prejudice. Maureen's "blood boils" when she sees people with impairment being teased or belittled. Janice works hard to ensure that all of her children are not harmed by having a family member with impairment, and Diane is protective of both her husband and child in the face of hurtful attitudes. Family members did seem to be exposed to prejudicial attitudes in a similar way to individuals, and did have to respond to the prejudice that they encountered, but the end result of the process did not seem to be as grave for family members as it can be for individuals with impairment.

#### *Prejudice and material restrictions*

Family members may modify their behaviour as a consequence of encounters with prejudice, as for example when Maureen avoided unnecessary trips to the shops because of the patronising pity she received there. It could be argued that this avoidance of certain social situations is a kind of barrier to being, in that it is a kind of restriction in activity in response to the attitude of others. However, there is not the

internalised judgment that is apparent in the examples that Thomas provides of barriers to being, such as internalising prejudicial ideas about impairment being ugly, thinking yourself unattractive, and therefore not going out. Maureen avoided unnecessary trips to the shops, but at the same time she described herself as a good mother and her child as beautiful; she was in no danger of internalising the negative attitudes to impairment that she encountered, and her sense of the value of her child and her family was not threatened.

I have argued that the families in this study did not seem to experience barriers to being in the same way as described by Thomas for individuals. This is of course not to suggest that families do not experience negative emotions. Parents were unhappy at times, perhaps because of impairment effect or because of disabling material barriers. Mary's son Ben has mild intellectual impairment. She was concerned about his poor reading, and avoided going into his classroom because she was distressed at being confronted there by his academic limitations compared to his peers. She also became frustrated when supervising his homework. Her distress on these occasions seemed to result from the frustrations of impairment, and therefore to be impairment effects. But when I asked her what she was most worried about, she replied "What is [his] job, what is [his] opportunity?" This concern that Ben will not be able to get a job appears to be the threat of a socially created exclusion for Ben that is also felt by Mary, rather than either an impairment effect or the impact of internalised prejudice on psycho-emotional wellbeing. Similarly, the emotional pain and frustration that Samantha described seemed to be the result of a combination of impairment effect and disablism rather than socially engendered undermining of psycho-emotional wellbeing. Samantha said that her family life was "abnormal", in that the family were always

splitting up to do things and could not do the things that their peers could do. The shortcomings of services also made Samantha pessimistic about the future. The negative feelings of parents such as Samantha and Mary are examples of the emotional impact of impairment effects and disabling material barriers. However, parents did not seem to experience the negative psycho-emotional impact of prejudice in the way that Thomas described for individuals with impairment.

#### *Findings in context of research literature*

This study has described mothers as affirming the value of their child, their family and themselves as parents in the face of encounters with prejudicial attitudes towards impairment. Mothers' understanding of impairment was inconsistent with prejudicial stereotypes about impairment, such as that their child is of lesser value or that impairment is the dominant attribute of their child or their family. There are reports in the literature of mothers using their understanding of impairment to resist the pathologising of their child with impairment (Kelly, 2005; Landsman, 2005; McKeever & Miller, 2004; McLaughlin & Goodley, 2008). Mothers readily accepted the opportunity offered in the interviews to describe the everyday and routine aspects of their family life. A willingness by carers to adapt this frame was reported by the originators of ecocultural theory (Gallimore et al., 1989), and seems consistent with a desire for mothers of children with impairment to claim an ordinary family life (Birenbaum, 1992; Blyth & Gardner, 2007; Goodley & Tregaskis, 2006; Kelly, 2005; Todd & Jones, 2003). My study is consistent with the work of Green (2003, 2007), who described the negative emotional impact of stigma on mothers of children with impairment. Green (2003) found that stigma added to the burden of care for mothers, but she subsequently (2007) reiterated that mothers experienced material

disadvantage, such as exhaustion, so as to affirm that disadvantage for mothers should not be viewed solely from the perspective of non-material harm.

### *Disablism and barriers to being in families*

Even though families did not seem to experience the socially engendered undermining of psycho-emotional wellbeing, the prejudice that they encountered nevertheless bespeaks disadvantage. Prejudice has an impact on family life; it matters to families, in that families may be fundamentally misunderstood by others as burdened by tragedy, or misperceived as having a child who is inferior, and this can make parents feel misunderstood, hurt and angry. Even though they do not internalise the stereotypes to which they are exposed, parents such as Diane, Laura and Maureen strongly object to their child or themselves being stereotyped as inferior or lacking. The issue that arises now is how, within the social model, to account for the experience of prejudice by families.

### A way forward

A major contribution by Thomas to theorising the social model has been to insist on both material and non-material dimensions in her definition of disablism. This study has suggested that the non-material dimension of disablism does not seem to hold in the same way for families as it does for individuals. This does not mean that non-material factors are therefore irrelevant to families from a social model perspective, because being misperceived by others is a problem for families.

One possible way forward here is offered by Nancy Fraser (2001). Fraser was not specifically concerned with the situation of people with impairment, but theorised

about the nature of disadvantage more generally. She noted that there is a polarised debate amongst theorists of social justice concerning the relative importance of material wellbeing, such as access to material goods and services, versus the importance of non-material wellbeing evident in theories of social recognition. Fraser argued that an adequate theoretical framework of justice requires consideration of both material and non-material conditions for wellbeing for disadvantaged groups. Fraser proposed that justice requires that all social actors have an equal opportunity to participate in society, and that there are both material and non-material prerequisites for individuals to experience what she calls “participation parity”. Fraser’s conclusion that both material and non-material factors contribute to wellbeing parallels Thomas’ consideration of these two dimensions in her definition of disablism. In contrast to Thomas, however, Fraser concluded that harm to wellbeing in the non-material dimension is not defined by the extent of psychological distortion or harm to identity. Fraser argued that the injustice of being misrecognised does not lie solely in the harm to identity that it causes. Rather, she argued, the harm done by socially and culturally institutionalised patterns of valuing lies is in the more general principle of the way they create and maintain unequal conditions for entering into social relationships for disadvantaged groups. In other words, disadvantaged groups do not enter into social relationships as equal partners with other groups because of the devalued way in which they are seen when they enter into social interactions.

When applied to families with children with impairment, Fraser’s understanding of justice suggests that when families are misperceived as bearers of burden or tragedy, they experience an injustice. This is because misrecognition means that they do not enter into social interactions with their non-stereotyped peers as equals. According to

Fraser, harm to the social actor lies not so much in the extent of the psychological harm caused by social and cultural devaluing, in this case about impairment, but in the extent to which the ability of those who experience devaluing to participate as equals with their peers is compromised. This is how Fraser applied her principle of participation parity in the non-material realm.

An advantage of Fraser's explanation as to why prejudice such as stereotyping constitutes an injustice for families is that it allows that families with a child with impairment experience injustice when they are misperceived, without requiring that their emotional wellbeing be harmed by misrecognition. According to Fraser, harm is done when social actors are prevented from entering into social relations on an equal footing with their peers because they are misperceived, whether or not there is emotional damage consequent on misperception. Thus Fraser's principle of participation parity gives a theoretical account of wrong done to family members when, through prejudice, they are misperceived, even though the psycho-emotional wellbeing of family members is not harmed in the same way as for individuals with impairment that Thomas describes. The benefit of such a theoretical account of the harm of stereotyping for family members is that it can give theoretical weight to the objections of family members to stereotyping without requiring that they too experience psycho-emotional harm.

Thomas understandably focused on the severe negative consequences of prejudice for individuals with impairment, because this aspect of the consequences of prejudice was apparent in the accounts women gave. In Fraser's terms, Thomas described a situation in which misrecognition resulted in serious harm to identity. However, Fraser holds

that misrecognition is always a wrong, even in the absence of psycho-emotional damage, because it violates conditions for participation parity.

Prejudice about having a child with impairment can also harm families when it works to exacerbate material barriers in family life. Prejudicial ideas about impairment in families, such as the idea that a family with a child with impairment should expect to be treated differently because they have a child who is different, may serve to increase the existence of material disadvantage of families, in the same way that social modellers have argued that the idea of impairment as tragedy has been so undermining for individuals with impairment (Abberley, 1987; Oliver, 1996).

## Conclusion

The impact of encounters with prejudice on family members of families with children with impairment leads to the following summary of the harm done to families in such encounters:

*Family members of children with impairment are affected by prejudicial ideas about impairment when they are misperceived by others as a result of prejudice such as stereotyping. Such misperception is harmful to families in that it prevents them entering into social relations on an equal footing with their peers, whether or not they experience the socially engendered undermining of their psycho-emotional wellbeing.*

## *Chapter 7*

### *Conclusion*

#### Introduction

I earlier suggested that disability should now be one of Williams' "keywords" because, in contesting the meaning of disability, the social model contests the causes of disadvantage for people with impairment. In this study I have considered the applicability of Thomas' understanding of disablism to the situation of families with children with impairment. I have suggested that the concept of disablism applies to families with children with impairment, albeit not entirely in the way Thomas describes for individuals. So family disadvantage might also be caused by disablism. This has consequences for how families with children with impairment are understood, and for the concept of disablism. This final chapter considers some of the implications of the findings of this study, both theoretical and practical, as well as possible directions that further research on disablism and family life could take.

## Understanding disadvantage for families with a child with impairment

### *Limitations*

Before considering the implications of this study, it is important first to acknowledge its limitations, and to consider the degree of generality and certainty that can be attached to its findings. This study represents one step towards answering the large question of the applicability and utility of the social model in regard to families with children with impairment. I considered the accounts of daily life of a small group of families. I obviously do not claim that the findings of this study apply to all families with children with impairment. The families in this study were clients of DADHC, and had children whose impairments were evident and visible at a first meeting. It may be that when a child's impairment is not visible, family members may experience different kinds of disabling barriers. The families in this study were purposively selected, and their situations varied. The conclusions I draw about their experiences of disablism and impairment effects represent tentative propositions about the experiences of families with children with impairment as a whole. Many of the experiences are consistent with others reported in the literature, but the extent to which these families' experiences of disablism are similar or differ from those of other families remains to be examined. I do not make claims about the representativeness of their experiences for the entire population of families with a child with impairment.

This study accessed family life by using a particular methodology, derived from ecocultural theory, in which the perspective of the family unit as a whole is obtained by interviewing the primary carer (the mother), who is the person most responsible for organising daily life. The points of view of other family members are obtained via the

mother. It may be that the perspective of other family members would yield a different view of family life. It may also be that if family life were accessed using a different method, different aspects of disablism would be revealed.

### *Theory of disablism and families*

Thomas proposed that disablism is manifested for individuals with impairment in two dimensions – in material barriers that restrict social activities, and in non-material barriers or limits on self-esteem and identity. I have argued that there are material barriers evident in family life for families with a child with impairment. Consistent with the early definition of disability of UPIAS, these material barriers are the result of the failure of social organisation to take into account the needs of families with children with impairment. There is evidence in family reports of restrictions in the participation of mothers in the paid workforce, restrictions in family finances, in family leisure opportunities, and in family interactions with services. These restrictions can be inter-related and can vary over time. These are instances of exclusionary social practices underpinned by an unequal relationship between family members and others.

In contrast, the non-material dimension of disablism does not seem to work in families with a child with impairment in the way that Thomas described for individuals. Family members did encounter prejudice, and it affected them, but they did not appear to internalise prejudice and their psycho-emotional wellbeing was not severely diminished. I have suggested that when prejudice results in family members being misperceived and therefore not being able to participate in social relations on an

equal footing with peers, even though the psycho-emotional wellbeing of family members is not undermined, such situations nevertheless should be considered as disablism.

There is considerable evidence that families are disadvantaged. The problem has been to identify what causes this disadvantage. Bringing the social model perspective to bear on the situation of families with children with impairment means asking whether family disadvantage is the result of impairment or whether in fact it is the result of disablism. For individuals with impairment, the distinction between impairment and disability has proved of great utility in shifting attention to the extent to which their disadvantage is caused by the social response to the impairment rather than the impairment itself. For families, the application of the social model offers similar benefits.

Distinguishing between impairment and disability helps to articulate the extent to which disablism rather than impairment causes disadvantage and the extent to which disadvantage for families can in fact be overcome. The social model draws attention to the way that persistent stereotypes about impairment and disability can work to create or maintain disadvantage. The disadvantage created by disablism ought to be addressed not as a charitable response to tragedy, but as a matter of justice, because all members of society should have an equal opportunity to access social goods. A society in which there is participation parity is a just society.

I described in Chapter 3 how families with children with impairment were in earlier times considered in the research literature to be ineluctably doomed to disadvantage and tragedy, but that this view of families then shifted to the more modern understanding that stress in families with a child with impairment was not inevitable, and varied with the sociocultural context of the family. Disadvantage for families with children with impairment continues to be an important theme in research. If, as I have argued, the social model understanding of disability also applies to families, this understanding can be brought to the existing body of knowledge concerning the wellbeing of families. By identifying those parts of known family disadvantage that are disablism, the social model can clarify the extent to which known disadvantage can in fact be changed. It may be that, as has happened with individuals with impairment, the idea that impairment causes disadvantage, and the undermining power of the idea of disability as tragedy, have prevented the full extent to which disablism causes disadvantage from coming into view. It may be that the vestiges of the earlier idea of impairment as a family tragedy work to undermine the developing understanding of the extent to which family disadvantage is rooted in social organisation rather than impairment.

The concept of disablism can be used to add a political dimension to ecocultural theory, the theory on which the method for this study is based. Ecocultural theory describes the core task of families as being the creation of a sustainable routine, and proposes that family wellbeing depends on the extent to which families are able to achieve this core task. Ecocultural theory aims to describe what daily life is like for families, rather than to prescribe how life should be for families. If disablism impairs a family's ability to create and sustain a meaningful routine of family life, then this

understanding can be used to inject an agenda for social change into the conceptualisation of family wellbeing provided by ecocultural theory.

In considering the application of the social model for families, this study points to a particular challenge faced by the social model. Traditionally, the social model has been used to view the context of the individual with impairment as disabling. The potential role of the family as a support for their member with impairment, as for example when mothers advocate for their children with impairment, presents a challenge for the social model to accommodate. If families mediate broader social and cultural disabling influences, they play a crucial role in either reducing or amplifying disablism. It is essential, therefore, that the social model come to grips with the influence of the family, because the family as an institution can play a key role in combating disablism.

#### *Research implications*

This initial assay of the applicability of the social model to families with children with impairment could be extended in many directions. This study used one particular version of the social model. Other versions of the social model allied with different methodologies might yield different insights. Families may experience other kinds of disabling barriers, material or non-material, that were not identified in this study.

Many questions await further exploration, including: How are exclusion and prejudice about children with impairment or their families manifested? How are prejudicial ideas about children with impairment and their families created and maintained? How prevalent are exclusion and prejudice for families of children with impairment? To what extent are the experiences of disablism of the families in the current study

representative of the experiences of families with children with impairment as a whole? What is the relationship between the disablism experienced by children with impairment and the disablism experienced by their family members? To what extent are children with impairment protected from disablism by their families? How does the impact of disablism on families vary with the nature of their child's impairment? What is the perspective of other family members, such as the siblings of children with impairment? How does the gendered nature of caring work, implicit in the experience of mothers reported in this research, impact on the experience of disablism in families, most particularly on mothers?

#### *Practice implications*

The idea that quality of life for families with children with impairment is shaped by socially created barriers and by prejudicial ideas, and not solely or principally by impairment, can assist families, services and the wider community. Identifying the effects of disablism in the lives of children with impairment and their families is the first step in preventing or overcoming disablism, and so allowing children with impairment and their families to achieve their potential.

This study identified a number of disabling material barriers in family life. Because disablism is socially created disadvantage, social policy should aim to reduce and overcome it. Social policy should therefore address such disadvantage as a matter of the right of all families to equal opportunities, rather than as discretionary aid for families. So for example policy that supports the participation of mothers in the workforce ought to enable women with children with impairment to participate if they so wish alongside their peers. Increased participation of mothers of children with

impairment in the workforce may reduce the financial disadvantage of such families. Financial support to compensate families for the non-discretionary impairment-related expenses that they incur will also reduce the financial disadvantage of such families. The social and cultural institutions which create and support leisure opportunities for all families need to consider families with children with impairment, so that these families have leisure options equivalent to their peers.

Involvement with services is a feature of life for families with children with impairment. The experience of the mothers in this study, consistent with many other studies, is that genuine partnerships between families and services are difficult to achieve. Family members can feel that they are not listened to and have little control over the services that they receive. This study suggests that disablism may be a reason for the power imbalance so commonly observed between families and services. It can be speculated that disablism ideas underpin the chronic funding shortages at an institutional level that require family members to demonstrate their neediness. At the level of service provision, recognising and addressing family needs will be constrained if service providers do not have the resources to respond, or are blocked from responding effectively because of disabling practices that restrict choice for families. Services will not be able to respond effectively to disablism if they focus on impairment and so fail to recognise the impact of disability on families.

Services will also be unable to respond effectively to family need if they are blocked from hearing what families have to say by their own prejudicial ideas. Services need to support the “natural” protective work of families and not reflect a distorted understanding of families. An intervention approach that presumes that families with

a child with impairment are different from other families has the difficulty that, to the extent that families with a child with impairment see themselves as like any other family, it is inconsistent with how families see themselves. The idea that these families are different from other families, because they experience particular stresses or sorrows, or even disablism, has this shortcoming. If families with a child with impairment see themselves as like other families, then a framework which assumes that they are different is unlikely to be accepted by the family. Intervention offered under such a framework may be not accepted by the family because it is inconsistent with the family's view of themselves.

This study suggests that Thomas' understanding of disablism applies to families; material barriers to wellbeing exist for families as well as for individuals with impairment, and, although non-material barriers do not seem to operate in the same way for families as for individuals, prejudice also poses challenges for families. The idea that disablism causes disadvantage along with impairment has many implications for how families with children with impairment are understood and how they can be best supported in institutional, organisational and interpersonal interactions.

Finally, and perhaps most importantly, families may also benefit from using the social model as an advocacy tool. Much of the disadvantage for families, such as the restrictions in maternal employment and family leisure, and the financial costs, which might otherwise be understood by family members as the consequence of impairment, can be reframed as disabling disadvantage that can and should be changed.

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